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# The Dance to Death: the Aesthetic Experience of Dying

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## Declaration

This thesis has been composed by me, is my own work and has not been submitted for any other degree or professional qualification.

Signed: \_\_\_\_\_

Dated: \_\_\_\_\_

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## Acknowledgements



*Les Deux Solitudes*, linocut atelier rosepink (Montreal, 2012)

They didn't speak. Words were powerless now. Like a pair of dancers who had stopped mid-step, they simply held each other quietly, giving themselves up to the flow of time. Time that encompassed both past and present, and even a portion of the future. (Murakami, 2014: 324)

For Jane, with love

This thesis is the realisation of long-held dream that I thought would remain just that. Jane opened many doors for me and closed others behind her. My passage into the world herein was only possible with her parting; this is my closure of her loss.

My entry was encouraged by Katie Alexander; we share an interest in the achievement of big stuff for the over fifties. En route Team Canada – my sister Rose and Sylvain, and Team Belgium – my brother Wilf and Gélise, were there to cheer me through the dark, damp bits. Clodagh Ross provided compassion and continuity while seeking clarity to my obfuscations. My supervisors Professor Tonks Fawcett and Dr Marion Smith guided me when I strayed from the path, as I frequently did, supported my wobbly knees and kept the faith that this could and would be done. Finally, the examiners of this thesis, Dr Rosie Stenhouse (Internal) and Dr Fiona Cowdell (External, University of Hull) provided apposite comments.

To them all, a thousand thanks and to paraphrase Jane “There are [many] ways of marking my passing [the viva]. Have a party. Drink Loire fizz and fine whiskies. Eat cake and chocolate ice cream. Tell terrible jokes. Play the piano, sing very loud and out of tune. Have a laugh. It's your right.”



## Abstract

This study explores the shared experience of one woman's ovarian cancer, from diagnosis to death. The disease, known as the silent killer, is difficult to diagnose with the majority of women presenting with vague symptoms and advanced disease. It is difficult to treat, necessitating both aggressive chemotherapy and radical, eviscerating surgery. In 2011, around 7,100 new cases were diagnosed in the UK; in 2012 around 4,300 died from ovarian cancer. If diagnosed early, 90% of women survive for more than five years but only 5% survive if advanced disease is found on first presentation.<sup>1</sup>

The woman with ovarian cancer in this study was my partner. During her illness this research did not feature as such but we were both aware that there might be a sense of something unfinished after her death; she gave her full support for whatever I subsequently chose to do. In this thesis I explore and investigate our shared experience using documentary materials from the Illness Period, the eleven months from diagnosis to death. The thesis is in three parts, each with three chapters. In broad terms, Part One concerns the *Form and Function* of the study comprising the impetus for the research, its contextualisation in the literature and the approach to the inquiry. Part Two, *The Dance to Death*, describes the illness experience with recourse to the literature as appropriate. Part Three, *The Aesthetic Experience of Dying*, connects the narrative of the Illness Period from Part Two, with insights from German Idealism as embodied in Schiller's *Letters on the Aesthetic Education of Man*. These and many of Goethe's writings were my late partner's own area of doctoral study. They are used here to provide a means to further explore some aspects that emerged from the Illness Period. The research question addressed in this study is: What can be learnt from a shared experience of living with and through a life-limiting illness?

Dance emerged early in the study as a metaphor for the movement of our bodies through that time. The dance appears in three ways: first as quotidian life between health care appointments and everything else, secondly as an element of the methodology in the dialogue between the narrative and the literature, and finally in binary synthesis. This is the resolution of the tension between two opposing concepts, for example living and dying, and is taken from German Idealism as a mode of inquiry to understand aesthetic experience. The Illness Period is described in some detail as an analytic narrative reconstructed from the data with reference to the literature at relevant points. The role of the partner-carer in maintaining the balance between the life of

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1 Cancer Research UK 2014

small, sensuous pleasures and the realities of illness is necessary for the choreography of the dance.

The data include personal diary entries, blog posts and other ephemera. My own recollections have been captured through a series of self-directed interviews using storyboards to guide the storytelling. These data were augmented through access to the hospital and primary health records which provided information to fill gaps and correct inaccuracies. Drawing on Heidegger, a connection is found to home, being at home, homelessness and homecoming that provides a natural resolution to the tension between living and dying. Aesthetic experience, with particular reference to the dying person, is defined as a feeling of serenity of mood, a vividness of presence and a heightened self awareness. Three contributory aspects to the emergence of aesthetic experiences are identified:

- a sense of at-homeness and home as a sacred, peaceful place
- the inner court of family and friends that provides a context for sociability
- heightened sensory awareness experienced as moments of pleasure through taste, touch, smell, sound and sight

This study traces a path through one woman's experience of ovarian cancer, from diagnosis to death, using insights drawn from 18th century German Idealism as an understanding of the aesthetic. It is not a study of life and death but of living and dying with a spirit of well-being.

# Part One: Form and Function

The first part of this thesis sets out in chapter one the provenance of the study, provides some historical context and introduces the research questions that are addressed. The second chapter reviews the literature pertinent to the central tenets, illness and idealism. In the third chapter, the ethical aspects, research considerations and methods are described.

## I Finding Form

### *1.1 Introduction*

It will become evident to the reader that this thesis is a very personal study. All research is a journey into the unknown, fuelled by a spirit of inquiry and a thirst for knowledge. In that sense it is a quest, the researcher as hero conquering the research problem. This study is primarily a narrative inquiry as an investigation of a particular storied world. Working with highly personal stories is fraught with tensions of identity, confidentiality and privacy. Some of the data used in this study was already in the public domain in a personal blog and was therefore accessible to those who happen upon it.

To address the issues of identity, confidentiality and privacy, and to avoid the discomfiture of the reader I want to ‘out’ the two principal characters in this study from the beginning. They are Jane, who had advanced ovarian cancer, and me as partner, carer, and finally researcher. I have no formal evidence such as a signed permission document but she did give me her full, unequivocal approval of any research I might do after her death. Our families are also fully aware of this study and their identities are concealed. The precise dates of what I refer to as the Illness Period,<sup>2</sup> are not detailed in the study but work started within a few weeks of Jane’s death. The time from Jane feeling unwell to her death was approximately one year but the time frame is presented in terms of days, weeks and months without recourse to any particular year.

In this first chapter I set the scene and context for both the research and this thesis. This study is unusual in its exploration of a first-hand account of life experience limited by illness, and the influence on that experience of German Idealism.<sup>3</sup> I will first outline the relationship between

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<sup>2</sup> Defined in Section 3.5.1 as the time from my first awareness that Jane might be ill to her death.

<sup>3</sup> German Idealism is generally regarded as a philosophical movement primarily based on the work of Kant and Hegel. Goethe and Schiller are more commonly associated with German Romanticism. However, their interests were not confined to literary works and it is their association with philosophical ideas that makes the generic reference to German Idealism used throughout this work, more accurate (Brown, 2009).

the research, me and the person who was ill. I will then describe how the philosophical thinking of the eighteenth century polymaths, Goethe and Schiller, came to be pivotal to my understanding and interpretation of this illness experience.

## *1.2 First Steps*

The thesis title makes conscious use of figurative language. Entitling the study at the outset helped to provide clarity and consistency as the research progressed, essentially to stay more or less on message. A study with a minimum duration of three years, largely undertaken in isolation by a postgraduate student is, by its very nature, an organic, amorphous mass. We fall in and out of love with the topic, the method, the data and the entire exercise. It is a rite of passage that is exquisitely painful and joyful in equal measure. Yet we bluster on in the winds of change as myriad ideas and influences buffet the study into a concise, manageable state towards the intended degree. When I applied to study for a PhD, my intention was to review the current models of self care employed in Scotland and to then develop a personalised self care model to support cancer sufferers, their families and carers. As a former nurse, I felt obliged to locate what I wanted to do within a nursing context in order to gain admission. Self care and palliation were initial core themes in this study but I have not practised as a nurse for 30 years and have no desire to return to nursing. However, the direction of the research changed as the focus narrowed to what I really wanted to study although the orientation towards nursing endures.

The choice of the word, dance, in the thesis title is with figurative intent. I will utilise the meaning and organisation of dance in a general sense to illustrate what I perceived as the disruption of illness to an otherwise orderly, shared life. Whilst caring for Jane, I recall having a strong sense of choreographing many aspects of her, and our, daily lives. Whether this was to attend hospital appointments, to go for outings or simply to undertake everyday activities; all had to be subtly, carefully arranged to minimise negative effects for Jane. At times it was complicated and required the best of my logistical skills and forward planning, primarily to protect her from such necessary trivia. Yet it was also a time of joy, of small triumphs and simple enjoyment. To wallow in the impending gloom of approaching death seemed a wilful waste of such precious time. As will be seen, dance as a sequence of organised movements, became a central theme within the study.

The realisation that a loved one may be seriously ill is very worrying. When those concerns are then confirmed as hard fact, the effect is shattering. From the moment a life-limiting condition

is diagnosed, life can and will never be as it had been. Our reactions to such news and its consequences depend on many factors: who it is, what it is wrong and our relationship to the person concerned. What we do with this new and unwanted knowledge is dependent on our previous experience, our current circumstances and our worldview of disease and its treatment. Having shared such an experience what, in any of it, is worthy of academic research and why? There are possibly two reasons for the justification of research into the experience of caring for someone with life-limiting disease: to make sense of it and to discover if there is anything new to contribute to what is already known. There may also be many other factors in terms of personal interest, unresolved issues and a sense of something unfinished; fundamentally it is the belief that something might need to be better understood in both personal terms and thence for professional practice.

Jane was diagnosed in July; the treatment plan was chemotherapy then surgery. The reality was some respite then rapid decline and she died the following May. Those few statements suggest that the story is probably about her illness and demise but they could also be a catalyst to investigate some of the more abstract layers emerging from the basic facts. It is not uncommon for the bereaved to throw themselves into some new, time consuming enterprise. To use the experience as a basis for academic research is perhaps more unusual but not necessarily invalid. During my nurse training and subsequent nursing practice I had cared for many women with gynaecological cancers; these were my companion stories (Frank 2010). Such accounts accompany us through life that act as a guidance system assisting with our reactions to events or circumstances. However, my gynaecological companion stories were not helpful friends; they were harbingers of doom acting as constant reminders of the destructive and disfiguring nature of such cancers. Or at least they did not at first appear to be friends until I came to realise that although they foretold of difficult, unpleasant endings, that very knowledge was empowering. I was forewarned and could therefore be forearmed when that time surely came for Jane.

At various times during the course of my research, others have assumed or suggested that this study might be autoethnographic. Suggestions were made of recent studies such as personal bereavement following a father's unexpected death (Sehn, 2013) or the earlier traumatic loss of a brother (Ellis, 1993). But this study is not about sudden or unanticipated bereavement; I knew the ending from the outset. In chapter three, the methodological decisions and choices made are discussed in detail. For now I can state that I did not want or believe this research to be overtly autoethnographic, a term used in reference to "autobiographies that self-consciously explore the

interplay of the introspective, personally engaged self with cultural descriptions mediated through language, history, and ethnographic explanation” (Ellis & Bochner 2000: 742). While I accept that my role and position, as a personally engaged self, in this study is central, I am not the principal character or focus of attention; that privilege is for Jane. However, I do recognise my role as the researcher and reflexive agent in the unfolding narrative.

What this research first attempts to do is to understand the stories that were told as a direct result of the illness experience. These stories were recounted by Jane herself as the ‘official’ version of her illness and its progression, while others were told by clinicians to each other in their various roles. Their stories for Jane (and me) were verbal; when we did have a written account, it was secondhand and usually addressed to our general practitioner (GP). There is another version though of the central story, the one that drove me to research the experience and to write this thesis. The drive to narrate experience is, as Rita Charon has observed “to tell and simultaneously listen to a story that reflects and constitutes the self” (Charon, 2006: 74). Ultimately this research is the final act of caring, one last thing I could do to honour my partner and our suffering, to learn from our shared experience. And I have learnt that going deeper and deeper into a painful story is not easy or comfortable but ultimately it is justified. The tension of the research is resolved by finding peace and understanding.

In the remainder of this first chapter, I will give an overview of my background as researcher and of the biographical details, of us as a couple, that I consider relevant to the thesis. This is followed by an introduction to binary synthesis, an approach to the philosophical understanding of Schiller’s *On the Aesthetic Education of Man* (Schiller et al, 1967)<sup>4</sup>, that was central to Jane’s doctoral study of Goethe. In this study, I will argue that it was Jane’s philosophical understanding of the mode and content of Schiller’s writings on aesthetics that underpinned her attitude towards her illness. I will then give an explanation of the use of metaphor and its justification in this study. This leads to an outline of the research questions, that have been addressed by this study. Finally, there is an overview of the structure of the thesis and brief synopses of the subsequent chapters.

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<sup>4</sup> Edited and Translated, with an Introduction, Commentary and Glossary of Terms, by Elizabeth M Wilkinson and L A Willoughby. Henceforth quotations are footnoted and abbreviated to WW (Plenderleith, 1991: 13) and citations as Schiller et al, (1967).

### *1.3 An Earlier Dance*

I qualified as a general nurse in 1979 and worked in various positions as a staff nurse before becoming the charge nurse<sup>5</sup> of a general medical ward. An interest in education and research led to a nursing research training fellowship with the intention of studying the conceptualisation of nursing as a profession in its transition from ephemeral art to quantifiable science. Being registered for a PhD without a first degree proved to be beyond my capabilities at the time; I withdrew from academia and also from nursing. After retraining as a software engineer, a career in further and higher education progressed from lecturer to independent consultant. In addition to the nurse-researcher perspective there is another dimension and that is my role in adult education. It was during this time that I first met Jane in a professional context. All that we experienced was perceived as an opportunity for learning and mutual enrichment. Together, we had arrived at an interplay between thinking and doing, theory and practice by very different routes: Jane through her own doctoral study of secularisation in Goethe's autobiographical writing (Plenderleith, 1991) and mine through adult education and software engineering (Adamson, 1999). I will expand on the relevance of this complementary approach to our thinking in the next section.

We met when we were both employed in a major higher education project to establish a university for the Scottish Highlands and Islands. We then started our own educational consultancy which specialised in the use of learning technologies to support further and higher education. It operated with modest success for more than ten years, advising colleges and universities across the United Kingdom (UK). After some intense years of working predominantly through government agencies, we were becoming tired and jaded. Political changes were likely with a shift of the UK's administrative powers from centre left to centre right; there was also the banking crisis and its consequent austerity measures. By the autumn of the year preceding Jane's diagnosis, we had decided to sell our house, put necessities in store and pack essentials (including two cats) into an estate car and a small caravan. We headed for Eastern France in a bitterly cold winter. Our intention, once we were settled, was partly to start a small gardening enterprise but mostly to enjoy a European life in France, bordering Germany with a view of Switzerland. Jane was an excellent communicator being fluent in both French and German.

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<sup>5</sup> My title was actually ward sister, a gendered term is no longer used.

The following March we were back in Scotland, older, wiser and ready for the next challenge: where to live. Then, just as we thought we could start to enjoy life in Edinburgh, Jane was rather surprisingly diagnosed with ovarian cancer. It was surprising because we both believed ourselves to be fit and healthy, with a lifestyle grounded by a good diet and plenty of exercise. With hindsight, it did perhaps explain why she had lacked energy and enthusiasm abroad. It was not simply weariness of consultancy work, she was seriously ill yet apparently innocent of her condition. Our way of being, when faced with this most difficult of life challenges was not to dwell on why Jane had cancer, nor when she might die from the disease but to live what remaining life we had together in a state of Voltairean optimism “everything was for the best, in the best of all possible worlds” (Voltaire 2008: 4). The influence of *Candide* continued with the shared attitude that this great tragedy would be faced with humour. This is well illustrated by one of Jane’s last diary entries, when eating and drinking had become severely compromised and the morphine parched<sup>6</sup> her mouth ‘Wouldn’t you just die for lemon sorbet’.

#### 1.4 *Pas de Deux*

In this section, I will outline our philosophical pas de deux and some of its central themes. We had arrived, by very different routes, at a shared understanding: a whole is more than the sum of its parts. For Jane this is best exemplified (for those who can understand eighteenth century German) in her doctoral thesis in which she explores secularisation in Goethe’s *Dichtung und Wahrheit* (Plenderleith 1991). I have little understanding of German and therefore have only a general appreciation of her study. However, I know from years of living and working with her that the methodological tool she had used in her research was central to her understanding and conceptualisation of her world. This certainty and epistemological confidence may seem too strong but I will demonstrate the evidence is there in both her writing and attitude to her own mortality. The conventional approach to biography is through microscopic examination of all available materials. In realising that biographical work is equally autobiographical, it is actually kaleidoscopic “each time you look, you see something different, composed certainly of the same elements, but in a new configuration” (Stanley, 1992: 158). Accordingly, in this study I am drawing on both the material evidence I have that could be examined by any researcher and my personal, and therefore unique, knowledge of Jane and her life. And I am also drawing on my own experience of living and being with her. My memories are the jewel patterns of a kaleidoscope and not the penetrating spotlight of a microscope.

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6 Or as she said in Scots: ‘I’ve a terrible drouth’.



Goethe's *Dichtung und Wahrheit*, as it is generally referred to is actually entitled *Aus meinem Leben: Dichtung und Wahrheit* (From my Life: Poetry and Truth, 1811–33) and is a refashioning of his autobiographical recollections (*Dichtung*) and factual information (*Wahrheit*) (Mahoney, 2002). Jane's argument was that "Goethe's treatment of religion in *Dichtung und Wahrheit* may best be approached as a representation of sacral principles in secular form, as an interaction of these polarised opposites, by the methodological tool of binary synthesis" (Plenderleith, 1993: 297). This quotation introduces in a single sentence Jane's worldview. I will not pretend that I fully understand, despite her best efforts to explain, the nuanced meaning she drew from her study of Goethe's discussion of religion. What I do know is that it led her to part company with her Christian upbringing, to accept her own sexuality and for her conceptual understanding of life to be in terms of a virtuous interplay between opposing poles. She described this as 'a return enhanced', a way of recognising something that had perhaps been experienced previously but not then fully appreciated. Binary synthesis is essentially the interaction of two different concepts from which a third concept can emerge. This third concept is distinct in itself but contains all the elements of the other two within it.

In the dissertation for my masters degree in adult education (Adamson, 1999), I chose to investigate what was perceived then as a paradigm shift in post-compulsory education. The shift was towards student-centred learning, which had started with Dewey and the notion of lifelong learning and the subsequent move towards experiential learning (Jarvis 1995: 17). At that time, in my efforts to understand paradigms, I became aware of the work of Fritjof Capra and his exploration of the parallels between modern physics and eastern mysticism. I focused on what I perceived as the polarity inherent within the paradigm that results from looking at apparently opposing views and came to recognise this polarity not as a problem but as a potential for change. It was the statement of the Taoist principle "that any pair of opposites constitutes a polar relationship where each of the two poles is dynamically linked to the other" (Capra, 1975: 114) which led to this insight. In the dissertation I reflected:

In the context of this research, both paradigms<sup>7</sup> are needed because they are, after all, aspects of the same thing. There is little mileage in proposing a model of learning (and teaching) that attempts to discount much of what has happened in education over the last few decades. (Adamson, 1999: 62).

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<sup>7</sup> This is a reference to Gibbons et al (1994) and the proposed shift in the mode of knowledge production.

It was only when Jane read my dissertation that she realised the similarity between our two philosophical approaches to life; we were both driven to see polarities and their holistic relationship. We were not consciously choosing to adopt a particular philosophical orientation to our lives together but it was part of our mutual attraction. Nehamas, in his consideration of *The Art of Living*, is not recommending a return to classical Greece but the recognition of a philosophical basis to a particular worldview, “The sort of self one constructs as a result of adopting certain theories is not simply a biographical matter. It is, much more importantly, a literary and philosophical accomplishment.” (Nehamas, 1998: 2). If we take the time to read and understand a perspective for ourselves and not simply follow the way of our upbringing, then some intellectual accomplishment is also derived from that effort.

Our unity was brokered through binary synthesis, it was our common thread and an element of our slightly eccentric way of being. More properly, as a methodological tool, binary synthesis, emerged from the study and translation of Schiller’s *Letters<sup>8</sup> on the Aesthetic Education of Man<sup>9</sup>*. The Letters were the result of Schiller’s inquiry into art and beauty, and the influence of Immanuel Kant. The central concept of the treatise is that the play-impulse is the basis for all art and is the foundation for “the much more difficult art of living”<sup>10</sup>. The text is metaphysical and difficult to comprehend but it is essentially concerned with the apparent disassociation of what was once united such as sensibility and thought, feeling and morality, or science and art. The extensive study undertaken by Wilkinson and Willoughby, reveals Schiller’s letters to be a complex work with mathematical proportions, where regular intervals of three are used to develop his central tenet of a ‘third thing’<sup>11</sup>. Coincidentally, as I was unaware of this aspect of Schiller’s work until I started to write this chapter, a triadic structure to the research and to the presentation of the findings had already emerged. Schiller played a kind of language game between antithetical word pairs in a process of mutual subordination with his notion of two primary drives to the psyche:<sup>12</sup> one formal, the other material. From the interplay between these two drives, a third ‘play’ drive emerges. A more detailed explanation is given in the next chapter

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8 Schaper (1985: 154) defines *Aesthetic Letters* as the usual abbreviation for the full title.

9 The word ‘man’ here is translated from the German ‘menschen’ or human being and is not simply a male person.

10 WW: xi

11 WW: li

12 I use the term psyche in the same fashion as Hunt “to denote the complex mind, including both the conscious and unconscious mental processes, and sense of self” (2013: 28 fn1).

and I will later illustrate how this dynamic tension was evident in the illness narrative, in chapter eight.

### 1.5 *Dancing Metaphors*

So to the dance and an explanation of why it is more than a figurative contrivance in this work. Its emergence was entirely natural during the Illness Period. One particular day I became very aware of how our life together had become a series of dances, little step sequences, between the GP's surgery, the chemotherapy day unit and the hospital clinic; we danced attendance to their tune. I interpreted this as a loss of control and self-determination (Nordgren & Fridlund, 2001) and later as the temporal, medical disruption to our autonomy (Frankenberg, 1988). Then I remembered an image my sister, who is a printmaker, had sent me during the illness, of a naked dancing woman that is reproduced in the Acknowledgements. That realisation and subsequent visualisation of a female form moving through light and dark, has become an iconic metaphor for this study and its particular conceptualisation of the illness experience. The use of metaphor in everyday life and language are commonplace "Metaphorical concepts provide ways of understanding one kind of experience in terms of another kind of experience." (Lakoff & Johnson, 1980: 486). In this sense the metaphor is clearly a useful figurative device to write or talk about difficult or sensitive topics such as death, dying and disease. Consequently, the use of metaphor in relation to illness and especially cancer, is frequent both in terms of the disease process itself and in the course of the illness (Fawcett, 2011).

Susan Sontag was taken to the "kingdom of the ill" (Sontag, 1978: 3) by her cancer and wrote polemically about her experience not just of her illness but of the stigmatisation of disease. In doing so she framed our understanding of metaphors for disease and the experience of illness in the 20th century (Clow, 2001). For some, Sontag's stand against the use of metaphor has been welcomed as they came to terms with their own disease. Sontag's (1978) *Illness as Metaphor*, has been described as "an eloquent plea against metaphorical thinking in matters medical" (Stacey, 1997: 45) but also recognises that it is the power of metaphor that "makes the silence speak" (Stacey, 1997: 64). A contrasting view of Sontag that recognises the biological symptoms of illness, also sees the "coded metaphors that speak to the contradictory aspects of social life, expressing feelings, sentiments, and ideas that must be otherwise kept hidden" (Scheper-Hughes & Lock, 1986: 138). Using metaphors to tell the story of the disease and its processes provides a means for the ill person to distance themselves from the reality of their situation. The focus of the metaphor is on the disease, the illness and the effect upon the person and their illness

experience (Pierret, 2003). Metaphors are also coping strategies for the emotional work of nurses in caring for the dying through both bodily containment and distancing such as “switching on and off” (Froggatt, 1998: 335).

The dance of death appears in many European cultures, most often as the *dance macabre* (French) but also as *totentanz* (German), as an allegory for the universality of death, most often as a grotesque image but also in writing and music. Its origin has been traced to a now lost mural in the Parisian *Cimetière des Innocents* which depicted the fatal encounter of the living with death personified. It is a memento mori, literally remember you must die. Through a variety of metaphors and formats the meaning remains clear: death comes to us all regardless of age, gender or rank (Ooesterwijk & Knoll, 2011). Such representations are deliberately dark and intentionally morbid, nothing to do with the light frivolity of dance. Janesick (1984) employs the metaphor of dance to describe the qualitative research design process identifying three distinct stages: warm-up, exercises and cool-down. As the account of this research unfolds, the correspondence between these stages and the three parts of this thesis will become clearer. The role of the choreographer is to create the dance. The dance metaphor can be expanded to give a choreographic insight into the relationship and interplay between the carer as choreographer and the cared for who is both dancer and director of the dance as it progresses. The metaphor also serves as a reminder of binary synthesis as the interplay between opposite partners.

My purpose in using the metaphor of dance is partly an attempt to surface a lighter, more playful touch towards illness, disease and suffering which reflects our shared experience. There were some desperate, dark moments, but there was far more light, play and fun. The metaphor also acts as the central theme through the narrative and analysis in the thesis. Writing as a method of inquiry has been practised since the 17th century by both those concerned with science and the arts despite the respective associations with objective truth and subjective falsehood (Richardson, 2000). Within the social sciences the use of metaphor is everywhere “Metaphors organise social scientific work and affect the interpretations of the ‘facts’; indeed, facts are interpretable (‘make sense’) only in terms of their place within a metaphoric structure.” (Richardson, 2000: 927). But metaphors are not the only trope, those words and phrases which are used in figurative language to create an image (as a visualisation) of something over and above its actual meaning. Metaphor, where reality is framed through analogy when a figure of speech enables us to see one thing in terms of another, is the most widely used trope (Chandler 2002: 124). Burke (1941) proposes four master tropes: metaphor, metonymy, synecdoche and

irony. He claims their use is not purely figurative but that they also have a role in the discovery of truth. I suggest tropes may be essential to narrative inquiry and analysis, an idea I will develop in the next chapter. In addition to metaphor, other tropes are employed in the figurative language of illness writings:

... notwithstanding Sontag's passionate argument against metaphor, many medical anthropologists would contend that it is impossible to think of illness except by means of tropes. Progress occurs by merely replacing one metaphor with a less inadequate one. (Lambeck, 2003: 6)

Perhaps more importantly in this context, irony has a special place with regard to illness and treatment where irony may be foregrounded by the illness situation or at least its recognition, and that therapeutic discourse may be understood by the extent to which irony is recognised "Irony is thus both an element of self-knowledge and a perspective on it. Illness and treatment sometimes either ignore or objectify and exaggerate the will and agency of sufferers." (Lambeck, 2003: 16). For example, when Jane became bald during chemotherapy she quipped that she was 'too sexy for my hair'. This point is also recognised in teaching medical students where irony may be relevant in the narrative writing of clinical settings. It gives distance to the author enabling them to use it when "nearing a truth that is too painful to say" (Charon, 2006:170). It affords us the bittersweet option, a way to tell the nasty nice.

There is a perhaps a broader issue here regarding what constitutes literature and therefore non-literature, while ignoring a distinction between fact and fiction, and raises the question of whether this work is in the most appropriate genre. If illness writing is largely autobiographical or biographical, would a book, a literary account of the shared experience, not be a more suitable product? Does this deliberate use of figurative language not compromise academic writing? Perhaps a prose essay where the use of rhetoric, "the conscious fashioning of structure and figures of speech such as metaphor, to persuade an audience or readership" (Thomson 2010: 8) would be more at home. Yet persuading the reader is an essential element in the reception of an academic argument, indeed rhetoric has now been 'rediscovered' and recognised as "central to scholarly work and its production" (Coffey et al, 1996: 4). To close this section, the four tropes are defined and explicated in the following table using health-related examples, adapted from Chandler (2002: 140):

<b>Trope</b>	<b>Definition</b>	<b>Example</b>	<b>Intended Meaning</b>
Metaphor	Similar through analogy but different	That doctor's a bit Marmite	You may find you either really like or dislike a person
Metonymy	Substitution through direct association	The appendix wants to go home	A patient who has had their appendix removed would like to leave the hospital
Synecdoche	More inclusive term in place of less inclusive one or vice versa	That drip's nearly through	That intravenous infusion requires attention and a new infusion bag
Irony	Use of the direct opposite	This ward's a <i>great</i> place to work	This is not a good place to work

Table 1.1 Examples of Figurative Tropes

## 1.6 The Research Puzzle

Conventionally phenomenological approaches, particularly Gadamer's hermeneutical phenomenology, would be considered more appropriate to the study of lived experience (van Manen, 1990). But such methods describe a way of being in a particular world for research purposes, of living the experience of such a world. What does the researcher do if they have already had the experience and were not consciously in research mode at the time? Is the answer that the task of phenomenological research and writing is "to construct a possible interpretation of the nature of a certain human experience" (van Manen, 1990: 41)? But in this thesis I want to do more than interpret and explain. While I have no personal need to unravel the detail of specific events and episodes, their sequence is important in order to follow the narrative thread and unfolding story. I do not want to reduce the available texts to themes; somehow this work seems to be more than what is written. It is about bearing witness, the testimony of one who walked beside their wounded partner as she resorted to stories of living well to heal the pain of her suffering "As wounded, people may be cared for, but as storytellers, they care for others" (Frank, 2013: xx).

Prior to embarking on this study I gave serious consideration to writing a conventional book about my experience of caring for Jane. The therapeutic use of fictional autobiography as a mechanism for personal and professional development (Hunt, 2013) could have been advantageous. I could have explored the experience of caring for Jane and the pain of losing her within a fictional context. This would preserve the anonymity of her and our families but it would also permit some poetic license with the actual details. At the foreground of my thinking

were the most recent events of the illness experience, consequently the research was initially configured as a study of palliative care and its impact on one's sense of self. However, as the "research puzzle" (Clandinin & Connelley, 2000: 124) developed, so my thinking evolved. Initially the study was located within the once familiar territory of health care and its principal places of delivery: hospitals and hospices. Now, these familiar places were strange, not just in the sense of the sociological imagination (Wright Mills, 2000) but for me as an actor with a different role from that of the nurse. I had been a nurse who became a carer and is now a researcher yet these different persona are all part of my being. My conceptualisation of the study was advancing and moving away from what I perceived as the familiar. I now found a clinical setting to be not just strange but unfamiliar; one where I no longer belonged.

As I continued to read and explore possibilities, ideas coalesced around using existing materials that I had to hand. This is the potential "bricolage" that is used in a dialogue with the researcher as "bricoleur" (Levi-Strauss, 1962: 11 & 19). These materials included diaries, notes, email, blog posts and hospital correspondence. The bricolage would be supplemented with my own recollections of the illness period through a series of self-reflective interviews. Inspired by the mixed methods approach suggested in Ken Plummer's *Documents of Life* (2001), I attended a workshop that was run by Ken himself. In essence, in a world overflowing with personal documents, three broad variations on the story of life can be found (Plummer, 2001):

- Long-life stories – the full-length book account of a person's life written in their own words
- Short-life stories – more common, focused and may be from personal documents or from interviews
- Naturalistic life stories – these occur naturally and are the ones which people tell as part of their everyday life "they are simply present as part of society, and have not been shaped by the social analyst" (Plummer, 2001: 27)

By utilising existing material the research could be centred on a personal experience that had already happened. But would appropriate data be available? Initially two potential data sources were identified: existing email correspondence, hospital letters, diaries and secondly, my personal recollections of key events during the Illness Period. As will be seen later in the study, a third source was added when access to the relevant health records was obtained. In the context of narrative medicine "Students of narrative today are committed to close examination not of dead

texts but of living textuality and discourse, wherever they may erupt” (Charon, 2006: 41). This is an apposite observation in this context.

A particular issue has been whether the story of Jane’s experience, in which I had such a central role, should be conveyed in the third person, as if I was writing about someone else thereby distancing myself. With particular reference to academic writing and the construction of discourse “Writing is an act of identity in which people align themselves with socio-culturally shaped possibilities for self-hood, playing their part in reproducing or challenging dominant practices and discourses, and the values, beliefs and interests which they embody” (Ivanič, 1998: 32). In other words, a doctoral student writing their thesis does so in a way that is unique to them not only in the originality of the oeuvre but also in the intertextual way that they write as they try to gain membership of the Academy. This way of writing may seem unnatural, forced, stylised and difficult but the examining readers are looking for evidence of positioned performance and coherent argument. The relationship between author and subject is even more sharply focused in biographical studies where the position of the researcher is now reflected by the compound term auto/biography to accommodate the relationship “between biography and autobiography, as well as the divisions between self/other, public/private, and immediacy/memory” (Stanley, 1993: 42). Furthermore the role of the researcher and their experience of the research process should be recognised as central and made explicit in the research writing (Stanley & Wise, 1993). These polarities can be considered as binary syntheses, where the ascendancy of one can only be seen in the subordination of the other. The significance of the self becomes apparent in respect of others; we can only determine the boundary of private when we give regard to public.

Before the discussion on the development of the research questions, there is a final point which concerns the emergence of themes, and the extent to which they influenced the study. Customarily, thematic analysis looks across a data set drawn from multiple respondents and using the same instruments, for recurring themes and common categories. For example, interviews with different respondents or multiple case notes might be analysed for themes such as pain, temporal disruption or healing spaces. However, that is not to say that thematic analysis is irrelevant to this study where the data set is drawn from multiple sources and does not use a standard instrument. I have been aware of some common themes from the outset, through my ethnographic familiarity with the data. This thematic awareness has enabled a certain alertness to



particular features or expressions as I have shuttled back and forth through the weft and the warp of the data. The following themes have been evident to me from the outset:

- Illness / disease: on being or feeling ill, having disease
- Death / dying: fear of, preparation for, acceptance
- Body: embodiment, disfigurement, disability, destruction, metamorphosis
- Place / space: peace, comfort/discomfort, contentment/discontentment

As the study has progressed, I noticed the shift in the relative position of these themes in the landscape of my recollections of the Illness Period. At the outset palliative care, death and dying were in the foreground of my thinking, perhaps not unsurprisingly given the recency of Jane's death. By the end of the study these themes remain valid but the focus is sharpened and their prominence has waned.

### ***1.7 Aim of the Research***

The development of an appropriate research question to drive the inquiry was challenging. However, as the study progressed and I continued to struggle with what constituted a research problem in this context, I realised a narrative inquiry could accommodate both the academic requirements of doctoral study and my own reservations regarding a narrow focus. My logic was that what I was exploring in great detail was a series of events and experiences. To me they did not constitute a problem, they were simply things that happened. My most recent experience in caring for Jane was her death which initially distorted the focus of the study, placing undue emphasis on the end of the story. I was also distracted by the assumption that there is such a phenomenon as a good death which is obviously impossible to genuinely evaluate. This issue is discussed in the review of the literature in the next chapter. While death is clearly an important feature of the study, the intention of the research is to focus on good living as opposed to good dying. Death may be perceived as peaceful, pain-free, even graceful and an end to suffering. In that sense it may well be good for the person who dies but we cannot know, it is ineffable and those who continue to live are bereft.

The purpose of this study is to investigate and understand the events and experiences of a particular episode in my life, bounded by an illness observed<sup>13</sup> that ended in death. The aim is to ascertain whether anything can be learnt from this reflective revisiting. The experience of Jane's illness seemed to pass in a flash of diagnosis, treatment and dying; at the time, there was no time or emotional space for reflection. The research question addressed in this thesis is:

What can be learnt from a shared experience of living with and through a life-limiting illness?

The question opens the following sub-questions:

- What was the experience and in what ways was it shared?
- What is the narrative of this experience?
- What are the turning points or epiphanies in the narrative?
- What connections are there between this and similar narratives?
- What relevance does place have for this experience?
- What was the role of German Idealism in the emergent narrative?

The final section of this chapter outlines the subsequent chapters and indicates where these questions are addressed.

## 1.8 Overview of Thesis Chapters

Earlier in this introductory chapter, reference was made to the triadic structure of the study. The thesis is in three parts, each with three chapters. In broad terms, Part One concerns the *Form and Function* of the study comprising the impetus for the research, its contextualisation in the literature and the approach to the inquiry. Part Two, *The Dance to Death*, describes the illness experience in detail with recourse to the literature as appropriate. Part Three, *The Aesthetic Experience of Dying*, connects the narrative of the Illness Period from Part Two, with insights from German Idealism.

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13 This may appear as the objectification of the subjective, which it is in so far as I was acting as a nurse caring for a patient. Perhaps this was a way of distancing myself from the 'ultimate emotional labour' of dying (Smith, 2011: 134) otherwise it would have been just too difficult.

## 1.8.1 Part One: Form and Function

### *Chapter 2: Illness, Dying and German Idealism*

The literature reviewed in this study is a broad brushed landscape across many disciplines: nursing, medicine, sociology, philosophy and languages. The purpose of the literature review is to set two very different perspectives in play: illness and aesthetic experience. The first concerns the physical embodiment of life-limiting illness, death and dying while the second seeks to understand a particular interpretation of an aspect of German philosophy. Idealism developed from scientific naturalism and rational criticism as a more balanced view to empiricism and moral philosophy (Ameriks, 2000). To simplify the complexity, the chapter is divided in two with the substantive topics of illness and idealism. In the first part, there is a discussion and consideration of illness and disease, followed by the effects on the individual in terms of disruption and disability. I then examine the notion of illness trajectories: the course of the disease expressed in terms of physical, psychological and spiritual dimensions. Inevitably life-limiting disease leads to dying and death. The final section explores the wider, historical and sociological aspects of departing this world and the notion of the good death. Part two explores some aspects of 18th century German philosophy and briefly describes the basic tenets of idealism. The key protagonists of Weimar Classicism, Johann Wolfgang Goethe and Friedrich Schiller, and their working relationship are then introduced before a more detailed exploration of some aspects of their work. Specifically, there is an overview of Schiller's philosophical works and a more detailed explanation of his theory of aesthetic education. The chapter concludes with an introduction to Goethe's scientific studies and his conceptualisation of the Urphenomenon. In summary:

- Part One: Illness as disease, sickness and experience; illness trajectories; the art of nursing; palliation, death, dying and the good death
- Part Two: German Idealism, historical overview; specific contribution of Schiller's *Aesthetic Letters*; Goethe's scientific work and the *Urphänomen*<sup>14</sup>.

### *Chapter 3: Methodology*

The third chapter addresses the methodological considerations in the study and is arranged in three parts. These reflect the integration of ethics, knowledge and action as essential aspects of

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<sup>14</sup> Henceforth I adopt the anglicised version, Urphenomenon. There is an inconsistency in terminology in some texts (Bortoft, 1996; Seamon & Zajonc, 1998), but this does not detract from the intended meaning of primal or archetypal phenomenon. A more detailed explanation follows in Section 2.3.4.

the methodology. This is in recognition of a contemplative approach which characterises this study as the relationship between “head (knowing), the heart (ethics) and the hand (the art of action)” (Galvin & Todres, 2007: 35). This arrangement maps to the three sections within the methodology which first address the ethical aspects of the study (heart) before considering the underpinning theoretical framework (head) and finally the the methods used (hand). This order reflects the inherent logic in the approach by first recognising the moral principles relevant to the study, then the justification for the strategy used and finally describing how it was done.

The study draws on the phenomenological research tradition in the human sciences, particularly van Manen’s (1990) interpretation given his position as an educator and therefore the pedagogical orientation of his argument. His perspective is oriented towards professionals who come to study lived experience for what it can then teach others from the caring disciplines such as teaching and nursing (van Manen, 1990). The philosophy of the human sciences is therefore well suited to those not already affiliated (like me) to particular academic disciplines such as sociology, psychology or ethnography. A phenomenological approach frees the researcher from attributing meaning as constituted by the parent discipline and framing it in terms of social groups, mental types or cultures. Instead meaning is explicated in terms of living in our everyday existence and research is an act of caring as “we want to know that which is most essential to being” (van Manen, 1990: 5).

The narrative was assembled from data drawn from three principal sources, the first two pre-existing, the third created specifically for the study as detailed in the following table:

<b>Data Type</b>	<b>Data Source</b>
The Researcher’s Personal Records	Email correspondence between the researcher, the research subject and their family and friends; Blog posts written by the subject; Diaries kept by the both the researcher and the subject
The Subject’s Health Records	Accessed from both hospitals involved in the care of the subject and the primary health care provider
The Self-directed Interview <sup>15</sup> recollections of the researcher	Undertaken using the time frame of the study and storyboards constructed from key points and events of interest

**Table 1.2 Principal Data Sources**

The ethical practicalities associated with gaining access to the health records are briefly explicated. Finally, the method of constructing the analytic narrative is outlined from the data sources using three distinct time phases: finding, living, and dying.

<sup>15</sup> This approach was developed for the study and is detailed in Section 3.5.1.2

## 1.8.2 Part Two: The Dance to Death

The second part of the thesis is a detailed account of the entire illness experience from diagnosis to death and addresses the first three research questions. In addition to the three data sources, issues of inquiry are addressed in situ through recourse to the relevant literature. During the analysis phase nine distinct time periods, with three in each chapter, emerged. These provided a useful scaffold for the construction of the narrative. Each of chapter has an introductory synopsis of the time phase and concludes with a brief summary.

### *Chapter 4: Invitation to the Dance*

This chapter provides an introduction to the setting and situation of the study, covering the first two months of the Illness Period. It describes the discovery of life-limiting illness and its subsequent disruption to daily life:

Wondering – What is wrong with Jane, why is her belly swollen?

Finding – The tumour is found during an ultrasound and then seen by the surgeon

Planning – The oncologist's plan of campaign to attack the tumour

### *Chapter 5: Days for Dancing*

This chapter covers six months of the Illness Period as some sense of normality is restored and the disease is seen in perspective. It describes some of the precious moments lived with and in spite of the disease and its treatment:

Treating – The chemotherapy plan in action and then with some revision, which was also known as the great poisoning

Turning – Everyday life revolves around a continuous dance to treatment sessions and other hospital appointments

Living – Feeling free to roam in the hills around Edinburgh and the near beyond

### *Chapter 6: The Last Waltz*

In this chapter, which covers the last four months of the Illness Period, the short-lived success of the treatment is recognised. Preparations for parting by partying are made and celebrated:

Reviewing – The oncologist needs the surgeon to have another look

Part[y]ing – Family and friends visit from near and far as Jane gradually lets go

Dying – The last days as the dance fades from her

### **1.8.3 Part Three: The Aesthetic Experience of Dying**

The final part of the thesis reviews the analytic narrative from Part Two and makes the connections between what was witnessed and my understanding of Jane's personal philosophy. Two particular aspects are explored: the features of aesthetic experience as a facet of living while dying, and the return enhanced as the interplay between apparently opposite concepts.

#### ***Chapter 7: Narrating Illness***

This chapter first revisits the rationale for presenting the data as an analytic narrative and reviews the narrative of illness. There is then a consideration of the art and aesthetics of nursing. These two themes are then further explored through other stories of death and dying in comparison to those told in Part Two, thereby addressing the fourth research question.

#### ***Chapter 8: Aesthetic Experience***

The final two research questions are resolved in this chapter. Schiller's concept of the play-drive and its role in the sense of the aesthetic is revisited with exemplars from Part Two. This is further illustrated through ideas of sociability and *communitas* in relation to the interplay of family and friends. Then the development of Goethe's *Urphänomenon*, used here to provide a holistic understanding of place, is outlined before concluding with Heidegger's theory of homecoming.

#### ***Chapter 9: The Dance to Death and the Aesthetic Experience of Dying***

The final chapter reviews the thesis as a whole, reflecting on its three parts: Form and Function, The Dance to Death and the Aesthetic Experience of Dying. The evidence in response to the research questions is presented. From these, three contributory aspects to the emergence of aesthetic experience are identified:

- a sense of at-homeness as a sacred, peaceful place
- the inner court of family and friends that provides a context for sociability
- heightened sensory awareness experienced as moments of pleasure through taste, touch, smell, sound and sight

Finally, the thesis concludes with a summary of the contribution to knowledge that is made, the limitations of the research approach and suggested opportunities for further study.

## *1.9 Summary*

This chapter has set the scene and context for this study and its novel exploration of a witnessed personal account of a life limited by illness and early demise. The influence of German Idealism, the philosophical ideas of Goethe and Schiller and their relationship to the study have been outlined. The aim of the research and the structure of this thesis have been detailed.

## 2 Illness, Dying and German Idealism

### 2.1 Introduction

When I embarked upon this study, nursing was at its heart but the focus shifted as I realised I was viewing my experience from the end and not the beginning. Initially the dissertations I surveyed were concerned with palliative care, death and dying. The selected works are in no way intended to be exhaustive but include studies from overseas and from different perspectives: people with life-limiting illness, informal carers and palliative care workers. However, I did not find any longitudinal, reflective accounts of life-limiting illness of the shared experience of just two people. My interests then widened to include other works from the humanities where the connection is more enigmatic than obvious (see bibliographic table in *Appendix 1: Doctoral Studies Reviewed*). This study focuses on a particular philosophical perspective held by the dying person as a component of the shared experience and appears to be unique. Inevitably the structure of this literature review has undergone many iterations and revisions as I clarified its focus. The chapter title is itself a clue to the breadth of the substantive topics: illness, dying and German Idealism. It is difficult to make an elegant link to German Idealism and it therefore needs some justification. In Section 1.4, I identified the commonality in our personal philosophies and the focus of Jane's academic studies. While I recognise the following cannot be empirically evidenced, it is my belief that her knowledge and understanding of Goethe, Schiller and German Idealism was a substantial factor in her bearing of life-limiting illness. It was therefore necessary to have some understanding and appreciation of these obscure, specialised and tangential topics myself.

Only now as I write, have I come to realise that this study is not just a personal resolution to her untimely end but also to what we had intended to do once we had time, probably in retirement. It had been our plan to work on a publication that brought together the spirit of German Idealism with holistic inquiry. All the difficult German material would be explained to me by Jane and together we would write something that brought some of the idealised spirit of the eighteenth century to my understanding of systems. If I am honest, we would probably have never found the time, inclination or tenacity to complete such a task, being too busy with our active engagement in the world. But now there is an opportunity to demonstrate a connection between an appreciation of aesthetic experience and life-limiting illness. The chapter is structured in two parts as broad sections, each a substantive topic in its own right. Consequently,



due to limitations of space alone and not understanding or interest, the coverage of each may appear superficial:

Part One: Illness as disease, sickness and experience; illness trajectories; the art of nursing; palliation, death, dying and the good death

Part Two: German Idealism, historical overview; specific contribution of Schiller's *Aesthetic Letters*; Goethe's scientific work and the Urphenomenon

A further justification that lies beyond my own purposes and therefore connects with the interests of a wider audience is suggested by this quotation from a book published long after this study began:

The transformational experiences of dying people commonly reorient their attention toward their own inner life. A fresh and growing appreciation of the outer life around them emerges as a result. This reorientation to the inner life is a counterbalance to their usual sense of living with a contracting sense of time and gives them a sense of growing depth. (Kellehear, 2014: 214)

I want to conclude this introduction with a small dilemma that has arisen concerning the direction in which the literature review is written. By this I mean should it look back and across the topics relevant at the time the research puzzle presented itself, or should it be contiguous with the research and look forward to the conclusion? If the former, then the focus would be on illness, nursing, palliation and dying. But leaning to the latter, to do more than introduce phenomenology in particular, seems to anticipate, almost spoil, the ending. The problem is as much to do with the way I conducted the study as a continuous, iterative inquiry process. The solution then seems to be, as outlined above, to provide an overview of the two substantive topics, illness and idealism, with the emphasis on what was reviewed in the early stages of the study. Then, as will be seen in Parts Two and Three of the thesis, other literature is referenced as it becomes relevant and the focus becomes both narrow and kaleidoscopic.

## **2.2 Part One: Illness**

### **2.2.1 Illness and Disease**

In any discussion of disease and illness it is probably advisable to start with some widely accepted functional definitions as the two terms are often used in different ways but in the same context. One interpretation is "illnesses are experiences of disvalued changes in states of being and in

social function; diseases, in the scientific paradigm of modern medicine, are abnormalities in the structure and function of body organs and systems” (Eisenberg, 1977: 11). This distinction between disease as a pathophysiological change in the body and illness as the personal experience of that change is interesting. In the conventional medical model, disease is perceived as a uniform entity with specific properties whatever the setting. In turn, this is linked to the medical construct of health and normality. Deviations from normal values may be indicators of some disease process which can be confirmed by further diagnostic tests of the function and structure of organs (Helman, 1981).

Both Eisenberg and Helman acknowledge that the experience of illness is socio-cultural and personal; our response to feeling unwell has as much to do with folk traditions as it does to our acceptance of medical treatment. Yet while these understandings of illness and disease were apposite when I trained as a nurse, interpretations other than the biomedical model were starting to emerge. An alternative, biopsychosocial model was proposed that included the person as well as their illness (Engel, 1977). Nearly forty years on, the debate regarding a more holistic approach continues (Havelka et al, 2009). While aspects of the model have become more mainstream through health psychology and psychosomatic medicine, the tenets remain peripheral. It has been suggested that a ‘cross-border dialogue’ is needed as “the biomedical and the psycho-social schools of thought, underpinned by the well supported hypothesis that the complex enigma of human existence cannot be fully understood within the narrow boundaries of one or the other scientific community” (Junne & Zipfel, 2015: 1).

While these ideas are to be welcomed, the emphasis is on the negative construct of illness and disease as an opposite to health. In 1948, the World Health Organisation (WHO) defined health as “a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity” (WHO, 2006: 1). This ambitious statement that has been widely criticised for being idealistic and unattainable (Huber et al, 2011). The WHO vision though was one of global health, levelling the disparities between the wealthy West and other less well provisioned areas of the world. It has been suggested that the problem is viewed in an unhelpful way, as a dichotomy between health and pathogenic disease (Antonovsky, 1972). Alternatively, if disease is viewed as being one pole of a continuum with health at the other, the focus may be shifted away from the simplistic ill/well construct. If a salutogenic focus is adopted the continuum becomes a useful heuristic that recognises the human body as “inherently flawed, subject to unavoidable entropic processes and unavoidable final death” (Antonovsky, 1996: 13).

This view attempts to understand the origins of health and the factors necessary for well-being (Antonovsky, 1979). Therefore a person diagnosed with a life-limiting disease would not be viewed solely in terms of the extent to which they can be treated but with the attitude that they can be helped towards better health (Antonovsky, 1996). At first, this may seem counter-intuitive; how can someone with a terminal diagnosis live a healthy life?

Attempts to redress this imbalance have focused on patient-centred care and self-management particularly in relation to chronic, long-term health conditions (Glasgow et al, 2002; Glasgow et al, 2003). However, the current emphasis in UK health care policy is on the personalisation of care which may be compromised by the acceptance of the medical profession of the patient as an equal partner in the collective response to the individual's disease and their illness experience. More recent developments in the concept of person-centred medicine, where there is a contrasting relationship between values-based practice and evidence-based practice, appear to be gaining recognition within the UK Department of Health (Fulford, 2011) and, more prominently, in Italy (Sarsina et al, 2012). Inevitably for health care providers the focus remains on the health condition that brings the person to these services. The person is no longer viewed as someone in need of succour but as a consumer with choices. But if you are ill, feeling dreadful, do you really want to have to make a choice? Myriad issues are raised which may include more informed choices, economic arguments, therapeutic options as well as the ability to pay for particular, more efficacious treatments. When in good health making choices is generally easy but when faced with serious illness having to choose may appear, albeit unintended, tactless.

This is not to deny the real value and advantages for patients in being involved in the choices and decision making regarding their own care. But if such accommodation is made as a reaction to the traditional medical model which "overemphasised illness and professional authority" (Dahlberg et al, 2009: 266) and as an otherwise economic expedient, the real value for the patient will be negated. Ironically, while personalised care policies may be intended to be inclusive and provide choice, they can fail to recognise the simultaneous need for agency and inherent vulnerability of the patient (Dahlberg et al, 2009). Patient centred policies may appear salutogenic in their approach with an emphasis on well-being but the reality remains with the conventional, illness-oriented model:

Without an explicit understanding of well-being, which includes the existential dimensions of freedom and vulnerability, health care policies and practice may be in danger of unreflectively assuming that health is just the

absence of illness as well as of falling into the trap of seeing patients as only consumers of care. (Dahlberg et al, 2009: 267)

Therefore an existential and salutogenic understanding of both health and illness is needed for the astute healthcare consumer to make an informed choice. Compassionate care (Fisher & Freshwater, 2014) would make the necessary provisions for those who were either unable or unwilling to exercise free choice.

Again being wary of pre-empting later considerations, I will close this brief discussion of health and illness by introducing a philosophical perspective. Drawing on Heidegger, there is a fundamental tension between the scientific view in medicine as seen in the medical model, and the patient's understanding of the effect of illness on their lifeworld (Svenaesus, 2013). Furthermore, the human being with an illness or disease is viewed through a lens of medical science and technology where "the embodied complaints of the patient are taken out of the life-world context of human dialogue and replaced by a medical-scientific analysis only" (Svenaesus, 2013: 6). Even if this tension is addressed, it is further claimed that without phenomenological understanding of illness to privilege first-person experience, there is no challenge to the objective, medical and third-person account of disease (Carel, 2013). However, Carel appears unaware of Frank's work with first person narratives of the illness experience (Frank, 2007). If well-being is simply viewed as a continuum between being ill or healthy, then understanding the experience of what it is to be ill, may be overlooked. The insider view from academics with first-person experience of serious illnesses such as multiple sclerosis (Toombs, 1990), cancer (Frank, 2013) and rare lung disease (Carel, 2008; 2013) provide some balance to the otherwise potentially distanced and abstracted views of third-person accounts.

### **2.2.2 The Illness Experience**

The previous section ended with the introduction of the idea that the experience of illness as a phenomenon which can only be really understood from the inside out, as first-person experience. However, while Carel (2013) accords particular value to first-hand accounts, she acknowledges the need for both perspectives and also the considerable literature on the illness experience. In this section I want to highlight some aspects in sociological interpretations of illness that have emerged in the past forty years. More specifically, the temporal dimension of illness was relevant to my understanding of the illness experience at the start of this study.

Disease processes and illness experiences do not occur in a vacuum; they happen over time. This temporal dimension is described by Bury (1982) as ‘biographical disruption’, particularly in relation to chronic illness. He contends “illness, is precisely that kind of experience where the structures of everyday life and the forms of knowledge which underpin them are disrupted” (Bury, 1982: 169). The effects of this disruption may impact on both the ability to draw on material resources and on social relationships. In other words it becomes difficult for someone who is chronically ill to engage and reciprocate in social settings. This is similar to the idea that loss of self occurs as a direct result of the illness experience (Charmaz, 1983). The nature of suffering for those living with chronic illness has been found to feature “living a restricted life, existing in social isolation, experiencing discredited definitions of self and becoming a burden” (Charmaz, 1983: 170). While it may be important for health services and care providers to be aware of these issues, their identification may also reinforce negative views of the chronically ill. An alternative, emancipatory view would be research to help sufferers to understand the social systems in which their lives are embedded (Frank, 2001). This would also have the advantage of closing the third-person gap that persists through research that explains sufferers’ behaviour to experts so they can effect change rather than empowering the sufferers.

The notion of a “cultural performance of sickness” (Frankenberg, 1988: 13) where time has a symbolic value for both medicine and healing, adds a third dimension to the disease-illness dyad. Health care is provided at the time and pace of the service’s choosing; the availability of evening appointments with GPs being a case in point. For patients, it takes time to get better, to be healed and cured or at least restored. Sickness is distinguished from both illness and disease, as a concept that provides both a cultural and social framework “Sickness as cultural performance can be analysed in all societies even if a specific performance may be the denial of disease and the absence of illness.” (Frankenberg, 1988: 17). The idea of sickness as a performance perhaps has its origins in Parsons concept of the sick role which dominated the sociology of medicine until the 1980s (Burnham, 2014). In a study which contrasts the triad of illness-disease-sickness, from its first use in Twaddle’s 1967 doctoral dissertation, with Nordenfelt’s welfare theory of health, does so to make the claim that these concepts can exist without a general theory of health (Hofmann, 2002). The triad is defined, without recourse to the “vast, vivid and full debate” (Hofmann, 2002: 657) as:

*Disease* is negative bodily occurrences as conceived of by the medical profession. *Illness* is negative bodily occurrences as conceived of by the

person himself. Correspondingly *sickness* is negative bodily occurrences as conceived of by the society and/or its institutions. Occurrence here means process, state or event. (Hofmann, 2002: 657, original emphasis)

This simplicity is helpful, as is the avoidance of the full debate, as it aligns the three concepts with those from the WHO definition of health, stated above:

- Physical – Disease
- Psychological – Illness
- Social – Sickness

Hofmann finds these concepts to be different perspectives of human ailments that are neither mutually exclusive nor interdependent. Consequently he found it difficult to merge them into a concise definition. Finally, he contends that a definition of health is not needed for the systematic provision of services to address human ailments and also to avoid the paradoxical term health care “it might be more proper to differentiate between the terms disease treatment system, illness care system, and sickness rights system” (Hofmann, 2002: 668). In the UK these systems are supplied through the National Health Service for medical and nursing care, local social care services and the Department of Work and Pensions for financial benefits which may be payable in times of sickness and retirement.

However, this mapping has a tidiness that fails to address the ontological question of what it is to be human and experience serious illness. Returning to earlier works concurrent with the notion of the sick role, a distinction is made between healing and curing:

Medical anthropologic studies show that traditional healing in developing societies and popular health care in our own are principally concerned with illness, that is, with treating the human experience of sickness. Healers seeks to provide a meaningful explanation for illness and to respond to the personal, family, and community issues surrounding illness. On the other hand, biomedicine is primarily interested in the recognition and treatment of disease (curing). (Kleinman et al, 1978: 252, original parentheses)

The role of healer does not really exist in Western notions of health care, being generally confined to the work of spiritual or faith practitioners. Yet this quotation seems to suggest that the human response to illness as a physical ailment and as experienced in sickness which sets the person apart from their social group, is healing. That can range from simple home remedies, through the ever increasing provision in supermarkets for pharmaceutical products, to alternative

and complementary therapies. It can often be the case that people only seek expert assistance when they are really suffering; in the current vernacular, too ill for a duvet day.

The relationship between illness, suffering and what it is to be human, which could also be seen as a portent of value-based medicine where clinical decision making is informed by the inclusion of patients' values (Fulford, 2011), is conflated in this statement:

... an interpretation of illness is something that patients, families and practitioners need to undertake together. For there is a dialectic at the heart of healing that brings the care giver into the uncertain, fearful world of pain and disability and that reciprocally introduces patient and family into the equally uncertain world of therapeutic actions. (Kleinman, 1988: xiv)

This sense of uncertainty increases the tension of what might be revealed thereby adding to the suffering of both the patient and their family. Here the researcher must exercise particular caution to not compound the situational suffering they seek to study as:

What is at stake in these questions is whether qualitative research can enhance a recognition of suffering in society or whether research becomes, however unconsciously, an organizing practice through which medicine and society can avoid recognizing suffering. (Frank, 2001: 356).

During the early planning and design phases of this study, still raw with my own bereavement, I was acutely aware of the potential intrusiveness of researching the seriously ill. I also felt that there was a potential dilemma in the actual subject responses as there may be an element of performance; to give a particular account of the illness experience that might not be wholly authentic.

The distance travelled in the sociological understanding of health and illness was celebrated in 2003 with the 25th anniversary of the journal *The Sociology of Health and Illness*, with a conference and a 'Silver Anniversary Issue' (Dingwall et al 2003). The purpose of the edition was to explore lay understanding of health and illness (Lawton, 2003). Three earlier works were identified for their noteworthy themes that helped establish a common understanding of the illness experience at a time when the medical perspective predominated. These themes were "biographical disruption" (Bury, 1982), "the loss of self" (Charmaz, 1983), both previously cited, and "narrative reconstruction" (Williams, 1984). The last theme concerns "the conceptual strategies people employ to create a sense of coherence, stability and order in the aftermath of the 'biographically disruptive' event of illness onset" (Lawton, 2003: 26). While the understandings of health and illness are found to have broadened considerably in 25 years, there

is an interesting conclusion, “the research interview invites a particular type of (disembodied) talk about experiences of health and illness, one that calls for ‘sick’ and ‘healthy’ bodies to be given higher profile at both an empirical and a theoretical level in work on lay experiences” (Lawton, 2003: 36). This suggests that in the early days of the discipline, researchers unwittingly encouraged their respondents to, if not adopt, at least play the sick role.

### 2.2.3 Illness Trajectories

Before moving to the next section on death and dying, I want to outline a conceptualisation of the illness time frame widely used in the context of health provision, the illness trajectory as it relates to the provision of palliative care. The concept emerged in the 1960s as a result of research into the changing course of disease over time. The sociologists Glaser and Strauss were particularly interested in the organisation of hospital work in relation to the temporality of dying. They observed that in the clinical setting, work proceeds according to organisational structures which were not necessarily congruent with the illness course. There was a strict routine when particular tasks were undertaken such as bathing patients, administering drugs or providing food. Disruption or even chaos occurred if a patient worsened or required an unanticipated intervention. What emerged was the idea that a patient’s illness had two elements of a trajectory: it had duration and it had shape (Glaser & Strauss, 1968). Their primary interest was with the dying because it takes time and cannot be organised to accommodate other service demands such as the needs of recovering patients.

Neither duration nor shape use a purely objective physiological property. They are both perceived properties; their dimensions depend on when the perceiver initially *defines* someone as dying and on his *expectations* of how that dying will proceed. Dying trajectories themselves, then, are perceived courses of dying rather than the actual courses. (Glaser & Strauss, 1968: 6, original emphasis)

Over some years of study, a trajectory model emerged for the analysis of the management of the chronically ill. This led to further work on the use of the framework by nurses to develop models of care (Corbin & Strauss 1991). The major concept of the trajectory is defined as the course of the illness or chronic condition and which requires “the combined efforts of the affected individual, family, and health care practitioners in order to shape it. That is, to determine its eventual outcome, manage any symptoms, and handle associated disability” (Corbin & Strauss 1991: 162). But the authors recognised that trajectories were not prospective. They could be uncertain and although particular illnesses have a potential course, it cannot be fully



perceived in advance. Models and frameworks can have a dichotomous nature when they provide novel insights into particular phenomena but they can also be used in a more rigid, predictive fashion.

The choice of the term 'trajectory' has been attributed to the then contemporary space race and the curving path of a rocket (Frankenberg, 1986). It therefore emphasises the technological nature of society and health care which results in what might be seen as "instrumentalizing ... expressive aspects of sickness, so that while the physician's autonomy disappears so does that of the patient and all others involved" (Frankenberg, 1986: 618). Despite my earlier comment, the trajectory framework had a practical value for both the medical and nursing communities as it was able to some extent to predict when death would occur. This enabled health workers to determine how best to manage time from both the patient's and family's perspectives. But it also seems to have unsettled others:

I am not quite sure what the unfolding of the course of biological disease, their rejected metaphor, implied. Perhaps, it was a closed book whose pages, ruffled by the wind, gradually revealed the patient's fate, unless the physician by main force kept it closed and held back the power of the word by concealing it; or perhaps it was the petals of a malign flower that unfolded. (Frankenberg, 1986: 618)

This quotation struck me as curious in an otherwise academic and temperate article. Not quite a flight of fancy but evidence of a certain discomfort with devices that were intended to improve the care of the dying but instead their interpretation in practice missed a fundamental point. Yes, dying does take time but for a particular person that is *their* time, a solo performance. I am not alone in suggesting that dying is the one time when any constraints to service provision should be lifted and a suspended state entered until the natural conclusion is reached "while pharmaceuticals and elaborate diagnostic technologies must never be ruled out, the first priority of a truly humane science of health care must always be to attend to the lived patient and his/her way of being-in-the-world" (Aho & Aho, 2008: 163).

As both the world's population and life expectancy continue to increase, the demands on health service provision at the end of life also rise. The need to quantify the temporal and physical dimensions of care at the end of life is both a personal and public issue. Despite the concerns raised above, the trajectory model has been found to be a useful alternative to the traditional model where aggressive care was abruptly withdrawn and replaced with hospice or terminal care (Lynn & Adamson, 2003). The revised trajectory model facilitates concurrent disease modifying

treatment with symptom management as a blend of curative and palliative care. Different types of illness were found to have different trajectories, often represented as declining graphs (Lynn & Adamson, 2003: 9):

- Short period of decline – mostly cancers
- Long-term limitations with serious episodes – mostly heart and lung failure
- Prolonged dwindling – mostly frailty and dementia

These models have been further researched and developed in the specific context of palliative care with a focus on living well. Work with lung cancer patients, in particular, has identified three additional trajectories within the over-arching decline of physical illness: social, psychological and spiritual (Murray et al 2007). This composite trajectory demonstrates that while the social path mirrors the physical course of steady decline, the psychological and spiritual dimensions are more subtle and have a wave-line form of troughs in response to key events such as diagnosis, discharge from hospital and disease progression. In a later study that found carers well-being followed similar trajectories to those of the dying person, the authors also acknowledge the danger of stereotyping as a result of using such archetypal trajectories. To address the issue alternative explanations were sought “for example, carers drew on resources within themselves or from others to moderate the distress that might otherwise have occurred” (Murray et al, 2010: 4) While at the individual level the predictive value may be limited, it is claimed that there are important policy implications to ensure there is adequate provision for carers that are person-centred and timely.

To conclude this discussion of illness trajectories, once a diagnosis of life-limiting illness has been made, it may then be impossible to ignore the temporal dimension of the course of the disease. There is a persistent awareness of time in a different way, of the need to make the most of every moment, to live in the present. There may also be a sense of a boundary being reached, of the threshold between life and death. Another influential framework (Watts, 2013) in the care of the dying is *The Rites of Passage* (van Gennep, 1960). Drawing on existing anthropological accounts of ritualistic practices amongst traditional societies, the terminology has become embedded in sociological and anthropological discourse (Watts, 2013). For any significant transition from one stage to another of a person's life, such as birth, attaining adulthood, marriage and death, certain features can be discerned. These ‘rites of passage’ were for van Gennep a special category of

ceremonial pattern because they represented the transition from one situation to another. He analysed the patterns into three subdivisions: rites of separation, prominent in funeral ceremonies, transition rites which may be important in pregnancy and initiation, and rites of incorporation at marriage (van Gennep, 1960: 11).

However, van Gennep went on to assert that not all three types have equal importance, nor are they equally elaborated in the examples he used. The actual transition occurs across a boundary, a crossing or threshold which may have its own specific rites, for example purification rituals such as washing. These rites at the threshold are not rituals of union but of preparation for union. A good Scottish example is that of ‘first-footing’ at New Year when anyone crossing the house threshold for the first time in a new year must bear transition gifts of coal and bread to ensure the home is warm and replete for the ensuing year<sup>16</sup>. Each stage may therefore have its own rites of preparation for the next stage:

Consequently, I propose to call the rites of separation from the previous world, *preliminal rites*, those executed during the transitional stage *liminal* (or *threshold*) *rites*, and the ceremonies of incorporation into the new world *post-liminal rites*. (van Gennep, 1960: 21)

These rituals can be applied to transitions not only between social states but also to temporal periods and spatial zones (Turner, 1977). Froggatt recognised the rite of passage between life and death in her study of hospice care. She describes the transition into palliative care as the crossing of a boundary to a liminal space, a move from the secular to the sacred (Froggatt, 1995). I suggest that this can also be seen as a formalisation of the limen through the management of the boundary between living and dying. However, the process may actually begin informally at a much earlier point with the realisation that something may be very wrong.

The boundary between life and death has become framed by the medicalisation of health care at the end of life (Hockey, 1986). Yet within this framing, the balance is redressed with the emergence of the hospice as a place where the boundary with “the surrounding community is the site of maximal visible movement, a public space where the life/death continuum is powerfully suggested” (Hockey, 1986: 180). Nevertheless, palliative care has succumbed to medicalisation (Clark, 2002) although when this is to control pain and other physical suffering it would be difficult to argue against such measures. Now it is medicine and its artefacts, not “religion or myth, [that] are the mediators of death and the force that creates and stabilises the

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<sup>16</sup> I have not given a citation for this custom as I grew up with the celebration of Hogmanay and our house being first-footed by my father.

meaning of death” (Page, 2010: 21). As a consequence of this medicalisation, it is then unsurprising that the place of death has shifted from the home to a place of organised and medicalised care. It may now seem counterintuitive to believe that death can actually be coped with at home without all the apparently essential technological paraphernalia necessary for the good death. This point will be revisited in the next section which explores palliative care, death and dying.

#### 2.2.4 Palliative Care

For those facing death from life-limiting disease, it is the place and manner of their demise that is their greatest concern (Higginson & Sen-Gupta, 2000; Gomes et al, 2013b). When I trained as a nurse in the 1970s, I do not recall hearing the term palliative care, instead we spoke, usually in hushed voices, of terminal illness and used euphemistic language such as ‘the departure lounge’ for the single rooms near the entrance to every Nightingale ward. Dying in hospital happened in dimly lit side rooms, out of the public gaze, sometimes with a vigilant family at the bedside. A sense of the mood and attitudes of earlier times is conveyed here “Often the nurses feel that a lingering patient is taking more time than is proper, because there is no real hope for him” (Glaser & Strauss, 1966: 24). Dying appeared to be an inconvenient and uncomfortable truth that the health care system had failed and therefore needed to be kept aside from the mainstream bustle of hospital *life*. More precisely, it reflected the spatial separation of the prospect of dying from the business of living (Hockey, 1986; 1990).

Concern for the welfare of the terminally ill and the origin of the hospice movement is unequivocally attributed to Dame Cicely Saunders (Clark 2007). As a result of her pioneering work the world’s first modern hospice, St Christopher’s in London, was opened in 1967; but it was another ten years before Scotland had its first: St Columba’s in Edinburgh. Caring specifically for the terminally ill was not a new concept in the UK nor were places to care for the dying. However, that care was invariably alongside the chronically sick and other ‘incurables’; it was not until the late 19th century that the two were differentiated (Humphreys 2001). Hospice as a place for the care of the terminally ill, with its focus on “all curative and palliative measures” (Clark, 2007: 431) for the control of total pain, only emerged in the 1960s. The concept of ‘total pain’ came from Saunders’ recognition that medicine effectively abandoned the terminally ill patient when nothing more could be done for them, in the sense of curative treatment. She took

this moment to be when the active management of both physical and psychological needs, hence total, should begin (Clark, 1999b).

The shift from using the term hospice care to palliative care and the related palliative medicine is culturally significant. Notwithstanding her pioneering work, Cicely Saunders was also an excellent communicator, not perhaps unsurprising given her background as nurse-social worker-physician, who wrote many articles for a variety of publications (Clark, 1998; 1999). Consequently she was an important influence in the development of the care of the terminally ill beyond the UK. The Canadian oncologist Balfour Mount is credited with the use of the term palliative, but it is clear that in his design for the first palliative care unit in the world, located in Montreal, that he drew on Saunders hospice work in the UK (Shephard, 1977). It is also thought that Saunders started to use the term palliative, almost synonymously with hospice, following correspondence and contact with the Canadians (Woods et al, 2001). More recently it has emerged that Mount actually made an extended visit to St Christopher's Hospice to see Saunders' work for himself (Baines, 2011).

However, this international sharing of knowledge and experience in end of life care for the cancer patient does not explain why Mount decided to use the term palliative. The answer is one of cultural difference and sensitivity. Mount worked in Quebec, the French-speaking province of Canada, where the word hospice in a simple sense translates as home but more accurately means a home for the aged, the orphaned and the handicapped (Hachette, 2009). Mount did not want to use a term with such negative connotations.<sup>17</sup> In context, this may well be true but Saunders has the last word on the origin of the term palliative. She attributes its first use to Dr Herbert Snow, a surgeon at the Cancer Hospital, Brompton who, in 1890 published a book on the "palliative treatment of incurable cancer" (Saunders, 2005: xviii) that included the use of the opium pipe.

There appears to be a curious omission in the cited accounts of the development of palliative and hospice care: the role of the Marie Curie Memorial Foundation (1985) who provide both nursing home (in-patient) and domiciliary care services. Possibly it is the focus on cancer care as opposed to the care of the dying that has led to this distinction. Nevertheless it is an oddity and not one made by Saunders who acknowledged that there was much to learn from the Foundation about the suffering of patients with cancer dying at home (Saunders, 2005).

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17 A brief history of palliative care from a Canadian perspective is given on Montreal's Victoria Hospice web site at: <http://www.victoriahospice.org/about/history-victoria-hospice>

Evidence to support provision of home palliative care services suggests that the likelihood of dying at home is doubled where this is a reality (Gomes et al, 2013).

### 2.2.5 Dying and Death

Knowledge and understanding of death and dying have changed considerably since the medieval dance macabre. Attitudes are now directed towards holistic approaches with renewed interest in ancient healing practices and Eastern philosophies that embrace peace and compassion. The pre-occupation with health has left us unprepared for death and its inevitability, suggesting this is a transitional phase (O’Gorman, 1998). In the intervening hundreds of years, society has moved away from the actual process of death to its professionalisation, consequently death rituals have changed. Rituals to celebrate the rites of passage between this world and the next are now confined to particular religious groups such as Buddhists and Muslims (O’Gorman, 1998). Since the turn of the millennium, two particular shifts in relation to death are noteworthy. The first concerns the changes in the pattern of mortality worldwide between developed and developing countries, the positive gain in life expectancy, and the shift to degenerative from infectious conditions (Seale, 2000). The second relates to the palliative care practices of death and dying adhering to simple embodiment. People no longer hold clear views or experiences of death as the loss of the embodied person, blurring the former divisions between life and death (Kellehear, 2007). For example, a person’s presence can continue after death through social media, photos and video, and other forms of contemporary memorialisation (Woodthorpe, 2010).

The sociologist Allan Kellehear has written extensively on many aspects of death, dying and suffering. For example, on health promoting palliative care (Kellehear, 1999), the social history of dying (Kellehear, 2007) and his proposed reorientation of palliative care to be more compassionate and community-focused (Kellehear, 2012). Clearly, there is no room here for any detailed analysis or account of his work but I want to note the relationship he draws between dying and suffering. He argues that situating these two, perhaps obviously related concepts, in a broader context of cultural experience will be mutually beneficial to their understanding (Kellehear 2009). In essence, my interpretation of his analysis is that the research literature takes a narrow view which makes recurrent use of particular metaphors such as ‘hero’ and ‘wound’ to exemplify the characteristics of a particular type of suffering and dying, as a told through accounts of terminal illness. Consequently, other descriptions of dying from suicide, genocide or other types of death miss an opportunity for a more informed understanding of suffering in

relation to dying. In the context of this study, a resonant point is Kellehear's recognition that the place of dying may actually contribute to suffering. The dying person may accept that for practical reasons such as pain relief or fear of being burdensome, the hospice is the most appropriate place. The reality may be that their choice leads to other suffering as they lose not just the familiar comforts of home but something deeper and less apparent.

### 2.2.6 Sequestration

Many of us will reach a point in our lives when it no longer seems practical or appropriate to be cared for at home. We concede to the separation of all that is held dear and are removed to the care home or hospice to die, and thence to the funeral parlour. The headline rites of passage, birth and death, are no longer contained and managed within the confines of home. Technological dependency has led to the increasing separation of life processes for fear of misadventure. Dying has become a state-defined experience and death is sequestered from the urban elite and the rising social classes (Kellehear 2007) presenting modern society with two essential issues: the timing and place of death.

Sequestration as a sociological term describes the regulation of many aspects of social life. When related to the phenomena of death and dying in modernity, sequestration is being set apart from the lives of ordinary people which can include institutional settings such as nursing homes and hospices (Froggatt, 2001). Alternatively if sequestration is seen through a lens of domestic figuration, defined as "a social network encompassing family, other household members and a wider group of familiars" (Stanley, 2012: 3) then people are not separated from death and dying but continue to respond not as individuals but in terms of their social networks. Consequently, sequestration has not over-ridden the role of domestic figuration in death and dying but operates alongside (Stanley & Wise, 2011). However, while "not everyone has a 'dying'" (Kellehear, 2009: 394) as in the case of sudden or unexpected death, most of us do. The issue of where we die, particularly for cancer sufferers, has been the subject of research aimed at providing choice for the terminally ill. In a time series analysis of place of death in England and Wales from 2004–2012, it was noted that prior to 2003, while two thirds would prefer to die at home, less than one half actually achieve their preference (Gomes et al, 2012). The study found this trend is being reversed and there is now an increase in home deaths. However, this positive finding comes with a cautionary note "there is little evidence that patients who die at home and their relatives experience better care than those who die in institutions" (Gomes et al, 2012: 106). To

counter this finding, in a subsequent study the authors have found that the chances of dying at home are doubled if effective home palliative care services are available (Gomes et al, 2013). Paradigmatically, urban dwellers dying at home are likely to be better supported by professional services than those in a more rural place.

### 2.2.7 The Good Death

The idea of a good death had not really occurred to me nor was it a familiar concept from my nursing days. When I started reviewing the palliative care literature it seemed that ‘dying well’ was now a nursing concern and that the characteristics of the good death originate in hospices “where open communication, relief of symptoms, individual dignity and respect and acceptance of death are prominent features” (Costello, 2006: 594). Drawing on more than thirty years of interest in the social welfare of the dying, Emanuel and Emanuel (1998) proposed a framework for the good death. Key to the overall experience of dying in their model, is the recognition of the relationship between the fixed characteristics of the patient (such as age, gender and ethnicity), the modifiable dimensions of their experience (such as symptoms, expectations and spirituality) and the care-system interventions that could influence change. There is a reasonable overlap between this model and the factors identified as conducive to dying at home, particularly those relating to illness and the individual such as beliefs, wishes and inner resources (Gomes et al, 2006). The good death framework has influenced more recent work (Murray et al, 2007) including the Dignity-Conserving Care model (Chochinov, 2002; Ostlund et al, 2012).

The difficulty of researching the good death has been found to have no peculiar characteristics or reasons, but there is “a dearth of research on the views of patients and carers on the good death” (Kendall et al, 2007: 523). It has been claimed that the challenges and issues inherent within models of palliative care and their conceptualisations of death and dying, suggests that the home is the place for dying as part of the ordinariness of life as “a non-institutional, non-paternalistic approach is essential to achieving optimal outcomes for the person dying at home” (Rosenberg, 2011: 26). In an autoethnographic account of a mother’s demise, dying at home is seen as instrumental, “This is a home death. As a family we are creating a good death, a hands-on death.” (Hocker, 2011: 330). From a phenomenological perspective, it is suggested that the goal of palliative care can be better understood as the metaphor “the patient’s coming home” (Dekkers, 2009: 347). Here I touch on a point that did not really resonate with this study until much later and is explored in Section 8.5.



Despite the commentary above, it seems to me that it is only the living, those who remain after a death has occurred, who are able to judge what might constitute a good death. Attempts at evaluating the quality of the dying experience inevitably rely on third-hand accounts which may be victim to the needs of the bereaved to perceive the death as good even if it was not. An anthropological interpretation of the good death suggests that there is a need for control over the apparent arbitrariness of the biological event thereby dissociating it from social death. All deaths are then seen to conform to a general pattern necessary for the cycle of life (Bloch & Parry, 1982). But if control is not possible then this may result in 'bad death', those that "contravene expectations about where, when and how a person should die" (Langer, 2010: 88). Yet this might imply that sudden death equates with bad death which may not necessarily be the case. Bradbury (2000) has suggested there are three types of good death: the traditional or sacred, the medicalised and the natural. The first is for those with faith where death is "tempered by a sense of celebration, even joy but invariably married to medical intervention" (Bradbury, 2000: 60). With the second type, the locus of control shifts from the dying person to their carers who use techniques to ease pain and perhaps prolong life through technical intervention. The third type, the natural good death, is a reinterpretation of control and has two subtypes. In the first, the dying become active agents in the management of their illness. Medical interventions may be rejected and control may be extended to after death by eco-friendly acts such as biodegradable coffins and tree planting. The other type of natural death occurs with sudden, unexpected death in natural settings such as being at sea or while trekking. It was a good death because the "deceased was spared the stress and pain of a lengthy dying trajectory" (Bradbury, 2000: 61). To me this seems to be a consolatory death which is good for the person who dies suddenly in happy pursuit, and bad for the unprepared family and friends who are shocked by the unexpected loss. The features of good death then appear to be a balance that includes its predictability and "with relatives being made aware of the imminence of death, and its timeliness, not just in terms of age but also in terms of the duration of the dying period" (Komaromy, 2010: 54).

In this first part of the review of literature relevant to this study, I have explored some broad themes concerning illness, disease and sickness. The experience of serious and life-limiting illness has been considered including both first person and third person perspectives. As life-limiting illness inevitably ends with early death, the use of illness trajectories to plan and inform palliative care services has been outlined. Finally, contemporary views of dying and the concept of the

good death have been adumbrated. The review now moves to the second part and a consideration of 18th century German philosophy and selected works of the polymaths Friedrich Schiller and Johann Wolfgang Goethe.

### 2.3 *Part Two: German Idealism*

At the beginning of this chapter I stated that my justification for deviating from the main topic was that this study is about Jane and her dying. In order to have some appreciation and understanding of her experience as the narrative unfolds, I suggest some knowledge of her personal philosophy would be helpful. It would of course been much easier if as a linguist, fluent in both French and German, she had followed a more conventional path such as being a school teacher. Then it would have been easy to include a few choice quotations from Voltaire, Flaubert, Schiller and Goethe. But no, she spent seven years studying Goethe and Schiller not just in Scotland but at their University of Jena, and also in Weimar, home to Goethe. So, as the late sociologist Ian Craib entreated:

When we talk about a person who is dying we need to know at least something about their history and character (otherwise, ... we might end up attributing that person's normal attitudes to the fact that they are dying) and we need to know something about the experience of dying (292). ... There is a psychological and a philosophical dimension to our understanding of death and I think these are more important than the sociological, if only because they enable a critique of contemporary social scripts and roles that surround dying. (Craib, 2003: 295).

This second part of the literature review begins with a brief contextualisation of 18th century Germany and an outline of the philosophy of Immanuel Kant. The relationship between Schiller and Goethe is introduced followed by a detailed explication of Schiller's ideas of aesthetic education. Finally, the common understanding attained between the two men is illustrated through an outline of Goethe's scientific studies and his conception of the *Urphenomenon*. There is no attempt to replicate Jane's own scholarly contribution to Goethe's treatment of religion in his autobiographical works (Plenderleith, 1991; 1993).

#### 2.3.1 *Germany in the 18th Century*

Any philosophical movement needs to be understood in its historical context (Beiser, 2005) and this is certainly true of German Idealism. It emerged towards the end of the Enlightenment or Age of Reason, in the eighteenth century when advances in knowledge were no longer based on Christian faith but on scientific understanding. In Europe this was not simply due to scientific

advancement but a societal change following the Thirty Years War and the 1648 Treaty of Westphalia (Croxtton, 1999). The treaty included the first recorded use of the word 'secularisation' to indicate the transfer of both power and land from the church to the state (Plenderleith, 1993). War and societal upheaval continued in Europe from 1792 with the French Revolutions and continued through the Napoleonic wars which finally ended in 1815.

Despite the disruption and decimation of war, inspired by the environment of philosophical idealism, German Romanticism emerged as a significant literary movement. German scholars are more specific and refer to this as German or Weimar Classicism embodied by the works of Johann Wolfgang Goethe (1749–1832) and Friedrich Schiller (1759–1805) (Brown, 2009). In recent years the relevance and significance of the contribution made by both German Idealism and Romanticism has been recognised not least because they can now be seen as grounded in the more modern idea of human freedom (Redding, 2011). Another feature of the movement was its interdisciplinary nature that transcended traditional academic boundaries. Its works continue to influence other fields such as the humanities in general and more specifically art, literary theory and religious studies (Ameriks, 2000). The 250th anniversary of Goethe's birth in 1999 (Sharpe, 2006) and the bicentennial anniversary of Schiller's death in 2005 (Craig, 2005) produced a plethora of publications and renewed interest not just in their works but in the wider movement.

By the latter half of the eighteenth century the German philosopher Immanuel Kant (1724–1804) in his attempt to bridge the gap between rationalism and empiricism (Richards, 2002), had published three critiques on reason and judgement where he developed his system of transcendental realism. Essentially he determined that we can only know the world through our experience of phenomena (as sensed). This perception through ideas and not through material substance, is known as idealism (Redding, 2011). Aesthetics is now generally understood to be the philosophical appreciation of beauty and art but despite the section title of *Transcendental Aesthetics* in the *Critique of Pure Reason* (1781), Kant is really referring to his conceptualisation of sensual experience. It is only in his later work, *The Critique of Judgement* (1790), that his inquiry shifts to the consideration of taste in terms of beauty and art (Hammermeister, 2002).

The relevance of Kant and his understanding of form, matter and aesthetics to this study, is that his work informed and stimulated other writers and philosophers in both Germany and Britain at that time. In an attempt to unify the distinctly theoretical and practical parts of Kant's

philosophy, Fichte<sup>18</sup> had devised a system of idealist philosophy, *Wissenschaftslehre*, or a doctrine of science. He wanted to show that from a single, unifying principle came sensibility and understanding as the form and content of experience. Fichte gave Schiller an advance copy of his essay with its theme of reciprocal causality (Dahlstrom, 2000). As will be seen, this idea was later to become a central theme for Schiller's philosophical writings. Despite initial success, the subjective idealism of both Kant and Fichte gave way to the increasing criticism of the younger romantic philosophers, particularly Schelling and Hegel, who proposed a doctrine of absolute idealism, *Naturphilosophie*, or a philosophy of nature (Beiser, 2005). However, although Schiller was aware of these ideas, his interest remained with Kant's attempt to find transcendental principles for aesthetics. But these were simply reflections of a knowing subject on given forms; the dependency of the imagination on spatial and temporal constructs. Schiller wanted a more holistic appreciation that could account for the contemplation of beauty as a transitory path from nature to morality (Dahlstrom, 2000).

### 2.3.2 Goethe and Schiller

In the midst of this philosophical flux Schiller arrived as a young military physician and successful playwright, to take up a post at the University of Jena (Reed, 2002). Schiller was born into a military family and despite his desire to become a pastor, when he was 13 his father enrolled him as a cadet at the military academy or *Karlsschule*, founded by his patron Karl Eugen, Duke of Württemberg. It was the *Karlsschule* who assigned him to a medical training as one more suited to his temperament and to provide greater intellectual satisfaction. A particular strength of the curriculum was philosophy and the debates in aesthetics, moral philosophy and literature were to have a lasting impression (Sharpe, 1991). On completion of his studies in 1780, Schiller was discharged from the academy but not from military service. He had already had his first play, *The Robbers*, written while on sickbay night duty, performed with modest success which left no desire to be a poorly salaried regimental physician (Sharpe, 1991; Craig, 2005). In 1782 he deserted and escaped to stay with friends who supported him through his itinerant years until he found fame. By chance, at a performance of *Don Carlos* in Weimar, he met Goethe's patron, Karl August, who appointed him councillor (Craig, 2005).

Schiller had greatly admired Goethe in his youth but an early meeting while he was a cadet had not been propitious; Schiller found his idol to be egoistic and unapproachable. He was also

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18 Johann Gottlieb Fichte (1762 – 1814) professor of philosophy at the University of Jena.

envious of Goethe's easy rise to fame through his fortuitous personal and social circumstances. While Schiller recognised Goethe's poetic genius, the older man was unimpressed by the younger's wildness and deep commitment to Kant's abstraction (Reed, 2002). Despite these misgivings, Goethe found Schiller a position as professor of history at the University of Jena. Following his two year absence from Weimar while he toured Italy, Goethe returned but found himself disconnected from the Weimar circle. He needed someone highly intelligent to talk to and Schiller wanted a supporter for his new literary journal, *Die Horen* (The Graces). A formal invitation to join the journal led to their first real meeting, an awkward encounter which confirmed their differences "Goethe's commitment to empirical realities as against Schiller's to mental structures" (Reed, 2002: 102).

### 2.3.3 Schiller and Aesthetic Education

In Section 1.3 I introduced German Idealism and particularly Schiller's *Aesthetic Letters*<sup>19</sup>, as being significant to this study. Jane made extensive use of the mode of analysis identified by the translators in her own thesis (Plenderleith, 1991). This edition of the *Aesthetic Letters* is itself described as "a model edition of a classic text" (Beiser, 2005: 6). It is on this basis and my personal knowledge of Jane's regular reference to *binary synthesis* or her own preferred term, 'a return enhanced', that I believe this mode of thought to be central to her personal philosophy. The essence is exemplified in Goethe's famous maxim that "There is nothing worth thinking but it has been thought before; we must only try to think again." (Goethe, 1906: 1). An earlier thought or understanding is enhanced by new information and insights. First some background to Schiller the man and his philosophical works before a more detailed explication of the pertinent aspects of the *Aesthetic Letters*.

Troubled by the French Revolution, Schiller recognised that his interest in aesthetics might seem to be at odds with the turmoil of the political world. However, he argued that his focus on aesthetics was *for* the sake of politics as freedom could be found on the path to beauty (Beiser, 2005). Schiller's interest had been sparked by his desire to find objectivity in Kant's *Critique of Judgement*. While he concurred with Kant's distinction of the beautiful from things or objects, defining aesthetics as a judgement of beauty necessitated some challenge (Schiller et al, 1967).

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19 While Wilkinson and Willoughby have been commended for their translation and clarifications (Bentley, 2009) this is a dense text, with mixed page numbering, a parallel translation of the *Aesthetic Letters*, verso German, recto English augmented by a commentary, glossary and various appendices. To claim that I comprehend much of the work would be too bold but I have made every effort to understand it because Jane did and knew what it revealed.

He spent two years exploring the nature of beauty, then the moral and the aesthetic as the beautiful soul and finally the nature of the individual in society (Schaper, 1985). Schiller's insights on each of these themes were published as a series of letters and as an essay, further detailed below. The development of philosophical aesthetics in Germany, at this time when it was not a unified country but a series of individual states and principalities, resulted from two key factors (Hammermeister, 2002). First, there was resistance to communication with and in other languages; therefore philosophical discussions maintained an internal purity. Secondly, although German developments were self-sufficient, others responded without actually influencing them. The direct influence of the German aesthetic tradition can be traced down through German philosophers, for example, the emergence of phenomenology from Husserl, Heidegger and Gadamer. It is also an influence on the work of others such as Merleau-Ponty, Sartre and Ricoeur (Hammermeister, 2002).

In 1792 Schiller wrote to his close friend Christian Gottfried Körner, with whom he had lodged for a time in Leipzig, of his epiphany after studying Kant's *Critique of Pure Judgement*. He wanted to clarify his insights into the nature of beauty as an objective of taste, as previously doubted by Kant (Beiser, 2005). Schiller intended to overcome the Kantian dualism of nature and freedom, and the latter's insistence that morality lay in obedience which seemed to Schiller to be "a lamentable gulf between feeling and action, a denial of the possibility of the harmonious personality" (Sharpe, 1991: 135). His ideas would be explicated through his plan to write a book, in dialogue form, that he would call *Kallias*<sup>20</sup> (Schindler, 2008). Illness and other commitments intervened and the book was never written. However, in early 1793 Schiller did maintain a dialogue as a series of letters with Körner which were posthumously published in 1847 as the *Kalliasbriefe* (*Kallias Letters*) (Bernstein, 2002; Schindler, 2008). Recalling the earlier point regarding the introspective nature of German aestheticism, the development of a philosophical argument through correspondence may seem at odds with any genuine scholarly purpose. The epistolary letter form was popular at the time (Schaper, 1985) and it has now been recognised as having scholarly value (Stanley, 2012), but it may well have served to undermine and undervalue Schiller's efforts. Despite the considerable contribution made by Schiller to modern understandings of aesthetics, he is best remembered as a poet and playwright (Beiser, 2005; Craig, 2005) and not as a philosopher.

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20 The name Kallias is derived from the Greek *kallos* meaning beauty.

Following the Kallias correspondence with Korner, Schiller continued with his quest to teach the public about aesthetics (Beiser, 2005) by writing an essay, *On Grace and Dignity* “in a style that not only reflected but actually embodied his subject matter” (Curran, 2005: 21). In the essay he addresses grace and dignity in relation to the beautiful and the sublime in order to render them as “different kinds of pleasing appearances of moral virtue” (Beiser, 2005: 80). The real challenge for Schiller was to resolve Kant’s deliberate dualism between the moral and the aesthetic. The essay has a distinctive style, rich in rhetoric and aphorisms (Curran, 2005) but fails to resolve the central issue of a harmonious synthesis between morality and aesthetics. Nevertheless, it does hint at Schiller’s emerging interest in tragedy, unsurprising in a playwright “If the person were only a sensible being, we would see only suffering; but since he is also a moral being, we see him having a power over his sensible nature” (Beiser, 2005: 118). Witnessing someone physically suffering while appearing serene is for Schiller the union of the moral with the aesthetic, the noumenal with the phenomenal, reason over pain. This is Schiller’s attempt to reconcile Kant’s freedom of the spirit with a “morality of being as well as a morality of doing”.<sup>21</sup> In a later work on the nature of the sublime, the pleasure in tragedy can be found:

When we see in suffering the limits of our physical being, we feel displeasure, in the form of fear, horror or dread; but when we see our greater stature as moral beings, we feel pleasure, the affirmation of our infinite value above all that happens in nature. (Beiser, 2005: 259)

Schiller believed that aesthetics were important to quotidian life both publicly and privately, particularly with regard to community living. However, despite his educative intentions, he provides little discussion of art and while making much of beauty, his interest is more with the notion of the beautiful (Schaper, 1985). His purpose was to propose an alternative to both enlightenment and revolution which he argued had failed to overcome the ills of society. His solution was to encourage a movement towards the notion of the ideal as “a unifying moment of reason and feeling, beauty and morality” (Hammermeister, 2002: 49).

The way for humanity to achieve this ideal was through the enhancement of everyday life which would not only be easier, it would become “the good life” (Schaper, 1985: 156). There is an implicit sense of overcoming and moving beyond in Schiller’s proposals that connects with the later reference in Section 7.7 of enhancement as “going beyond treatment or health” (Williams et al, 2011: 718). Schiller develops his theory of drives (Hammermeister, 2002) in twenty seven

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21 WW: xxviii

letters first published in 1795 as three separate parts in his journal *Die Horen* (Schiller et al, 1967). A total of twenty seven letters may seem odd or even arbitrary, yet the aesthetic was not confined to the subject of the letters but also in the presentation of the text. There is a geometric, rhythmic pattern in the articulation of his ideas in both the relationship between the letters and in the actual phrasing of the text as binary syntheses (see *Appendix 2: Binary Synthesis*).

The entire text is structured in oppositional pairs which are mediated by a third term. These constructs are used to describe the mediating behaviours or drives, of aesthetic man between ideal and natural man. Schiller drew on Fichte's theory of reciprocity to elaborate freedom as coordinate between and not subordinate of, one drive with the other (Dahlstrom, 2011). These drives can be understood as man's powers, faculties or forces (Wilkinson & Willoughby, 2002). The essence of Schiller's argument appears in *Letter 12*<sup>22</sup> where he identifies two basic drives: first is the *Stofftrieb* or *sense-drive*, concerned with material reality and sensation; secondly, the *Formtrieb* or *form-drive* is concerned with rational necessity and morality. The tension between these polarities calls for a third drive, first appearing in *Letter 15*<sup>23</sup> as the *Spieltrieb* or *play-drive*. In *Letter 18*, beauty becomes the objective of this third drive:

Beauty links the two opposite conditions of feeling and thinking; yet between these two there is absolutely no middle term. The former truth we know from Experience; the latter is given to us directly by Reason.<sup>24</sup>

Nowhere in the *Aesthetic Letters* does Schiller actually define aesthetic experience but I suggest the quotation is an accurate description. Bentley augments, in parentheses, Wilkinson and Willoughby's commentary to provide a definition that the "test for the genuineness of (aesthetic experience) is that we emerge from it with no inclination to one kind of activity rather than another, but ready to meet any immediate challenge that life may present" (Bentley, 2009: 296)<sup>25</sup>. She also adds a contemporary interpretation of the two drives when she suggests that the sense-drive be perceived as a desire for content or stuff and the form-drive as the means to manage that content (Bentley, 2009). Essential to Schiller's conceptualisation is his belief that there is a temporal dimension to the development of the three drives. The sense-drive comes first as awareness of sensation develops. Self-awareness then emerges as the form-drive and with it the

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22 WW: 79

23 WW: 105

24 WW: 123

25 WW: lxxxiv



ability to reason and rationalise. Finally, “only out of the interaction of both drives can the will be developed or freedom fostered”<sup>26</sup> and realised through the emergence of the play-drive.

While Schiller was writing the *Aesthetic Letters*, he was asked by his publisher, Cotta, to review a recently published pocket gardening calendar (Benn, 1991). This proved to be a fortuitous request as Schiller was able to use the review as a vehicle for his concept of the ideal garden. The review is rarely considered in its own right but it does provide an empirical example for his theory of aesthetic education. Schiller contrasts the regular, geometric features of French gardens with the lawless freedom found in English gardens. The solution lies, of course, in the middle way of German, landscaped gardens which “would appeal in equal measure to both the intellect and the emotions” (Benn, 1991: 32). In the review, Schiller uses the palace gardens at Hohenheim as an example of a landscaped place that is:

... capable of leading the simple man to thought and the man of culture to feeling [that he regards] as a beautiful art form which is instrumental in bringing the opposing forces in man’s psyche into a harmonious equilibrium and hence in furthering the aesthetic education of mankind (Benn, 1991: 40)

In the *Aesthetic Letters* Schiller proposes art as key to the reintegration of man’s alienation with modernity and his own inner conflicts without losing the benefits of sophistication (Sharpe, 1991). Yet this had only seemed achievable through the abstraction of beauty as an art form, such as the appreciation of classical Greek sculpture. Now, in a minor work on gardening, does his theory find practical application. However, while Schiller was known to have enjoyed walking and living in the countryside (Benn, 1991) he used the word ‘nature’ to refer not to “the phenomena themselves but the phenomena regarded as part of an abstract notion of nature’s completeness and regularity, as well as of its innocence, perfection and harmony” (Sharpe, 1991: 177). In other words, it is in the synthesis of the natural landscape with human design that Schiller finds “the qualities which the ideal landscape garden must possess if it is to have an aesthetic effect on man” (Benn, 1991: 29).

The final point in this section on Schiller is regarding his own health. In 1791 he suffered a possible “tubercular empyema of one lung that ruptured through his diaphragm into his abdominal cavity” (Bentley, 2009: 280). He was never well again and each winter expected to die from further serious illness. His continuing ill health gave him time to devote to his interest on

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26 WW: xcii

aesthetic matters. However, pressure of work at the University of Jena and commitments to publishers led to anxiety that compounded his fragile state. In his later correspondence to the end of his life “we read time and again that cramps, breathlessness and numerous other physical discomforts have kept him from work. One frequently has the sense of someone kept alive by sheer force of will-power” (Sharpe, 1991: 119). This information adds both a poignancy and a sense of the remarkable achievement of his efforts. It may also to some extent explain his particular interest in the aesthetic and tragedy thereby enhancing its value in this context.

### 2.3.4 Goethe’s Scientific Studies

Despite his ill health and consequent financial difficulties, Schiller had many supporters. Goethe especially was in contact through letters and visits on an almost daily basis (Bentley, 2009) until Schiller’s death in 1805. Goethe is credited with the shift in Schiller’s thinking away from Kantian dualism of nature versus freedom, forcing him to reconsider his concept of wholeness. In Goethe, Schiller saw a man who was a well rounded and fully integrated person, the perfect dynamic embodiment of his personality theory (Schiller et al, 1967). But Schiller had to acknowledge that for Goethe “the ideal of wholeness was only to be achieved as a changing pattern in time”<sup>27</sup> and not the static state of his initial conception.

Unlike Schiller who relied on abstract ideas and notions to shape his theories, Goethe preferred to start from the close observation of a particular phenomenon to build an understanding of the whole (Sharpe, 1991). Goethe’s approach to science was through the eyes of the artist who saw an aesthetically pleasing work of art as one which “re-presents traces of lived experience in the meaningfully interconnected array of the textured surface of its physical medium, whether in paint or marble, in the sound and look of language, or in the undulating figurations of the dancer’s body” (Stephenson<sup>28</sup> , 2005: 563). He was at odds with his contemporary scientific community and disliked mathematics, mechanics and astronomy which relied on a “system of quantitative signs [that] cannot adequately represent what we know qualitatively through experience” (Williams, 1998: 259).

Trying to understand Goethe’s scientific method and its relationship to binary synthesis, has presented something of a challenge. My approach has been to work first from the Germanists’

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<sup>27</sup> WW: xxxix

<sup>28</sup> There is a serendipitous trinity here with the introduction of Roger Stephenson, Emeritus Professor of German, University of Glasgow who was Jane’s doctoral supervisor. His supervisor was Professor Elizabeth Wilkinson, University College London, co-editor and translator of the *Aesthetic Letters*.

interpretations and explanations (Schiller et al, 1967; Sharpe, 1991; Stephenson, 2005), and then move to more interpretative accounts (Bortoft, 1996; Seamon, 1998; Zajonc, 1998; Wahl, 2005). Goethe's scientific method is not a precise set of steps to follow but a way of doing science that involves "heightened methodological awareness and sensitivity to the way we engage in the phenomenal world" (Holdrege, 2005: 27). Yet others cannot resist reducing the complexity by step-wise refinement (Wahl, 2005). In Section 1.3 binary synthesis is mentioned but not defined. My rationale is that I felt it was necessary to outline the relevant aspects of the *Aesthetic Letters* where the synthesis is employed in an elegant but abstract word game, termed by the translators as "binary synthesis"<sup>29</sup>. In collaboration with Schiller, Goethe developed a novel approach to writing as "aesthetic discourse" (Stephenson, 2005: 554) whereby the inter-related complexity of natural and cultural processes were re-enacted in language. Their literary alliance is now referred to as "Weimar Classicism" (Reed, 2002; Stephenson, 2005) where a longing for abstraction is countered by the need for the particular in a universal perspective and it is "the function of the aesthetic to provide this stereoscopic perspective by 'epitomizing' human significance in a particular form" (Stephenson, 2005: 562).

Returning to Goethe's scientific work, a topic of early discussions with Schiller was his idea of a primal plant or *Urpflanze* "which he insisted he could actually see in all individual plants" (Reed, 2002: 102). Schiller was unimpressed and remarked "it was a fine idea, but an idea, not an experience" (Williams, 1998: 266). Initially it had appeared that the two lacked any common ground but something sparked their interest in each other. They came to see themselves as "the contrasting halves of an ideal human and poetic wholeness" (Reed, 2002: 103); a living binary synthesis where the concepts from each would engage in an interplay of subordination and reciprocation. While Reed (2002) recounts their mutual influences in their dramatic and poetic works, Williams (1998) credits Schiller with encouraging Goethe to be more methodical in his scientific studies by including theory to balance his observations and experiences. Goethe's interests were not confined to his search for a primal plant but included all of the life sciences, which he termed morphology or the study of form. A development of this idea can be found in work on semantic category recognition or why a labrador dog is 'doggier' than a dachshund (Rosch, 1987).

Goethe was a passionate scientist for whom research was an ongoing mediation between direct experience and the tradition of the researcher (Steuer, 2006). In the context of this study, his

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29 WW: lxxxvii

most relevant scientific work is the *Zur Farbenlehre* or *Theory of Colour* first published in 1810 (Goethe, 1970). Goethe had attempted to refute Newton's colour theory, an exercise which proved to be ill-fated (Williams, 1998). However, it is his use of metaphorical language, cautioning against the use of signs for phenomena (Steuer, 2006) while seeing with the mind's eye, as the scientist's observations (Stephenson, 2005) that is apposite here. I suggest that part of the continuing attraction of the text is not the discredited theory, although there is some more recent evidence in its support (Zajonc, 1998) but the manner in which unorthodox ideas are presented. His purpose is to induce in the reader "a state of mind in which thought and perception become one" (Stephenson, 2005: 571). When this state occurs, the Urphenomenon, which can be understood as the primal phenomenon, appears (Bortoft, 1996; Seamon, 1998), something he had been searching for in his earlier plant studies but which he now found through his understanding of colour. Essentially, Goethe realised that there is a reciprocal relationship between light and darkness; without darkness, light cannot be perceived. From this interaction colours emerge which he referred to, in his figurative style, as the "deeds and sufferings of light" (Seamon, 2005: 92).

The point is not the correctness or otherwise of the theory but that the colours perceived in everyday experience can be understood as having "an intrinsic necessity and therefore are understandable in themselves" (Seamon, 2005: 96). The Urphenomenon is not an easy concept to understand despite the various interpretations (Heinemann, 1934; Bortoft, 1996; Seamon, 2005). Nevertheless, there is something curiously attractive to the theory which perhaps speaks to a basic human desire for wholeness. A few apparently random lines will be interpreted by the human brain into a recognisable form or gestalt; a glimpse of someone passing in the street leads to their recognition. This phenomenon can be explained through the different functionality of the brain's right and left hemispheres (McGilchrist, 2010). Simplistically, the left hemisphere is concerned with 'what' as individual bits of information while the right hemisphere, preoccupied by context, relational experience and emotion, is concerned with 'how' and making something whole, again a gestalt. Consequently until recently neuroscience was more interested in the overall functionality of the brain and not the individual function of each hemisphere. Now the role of the right hemisphere is recognised as it delivers the new as "the primacy of experience" (McGilchrist, 2010: 179) while the left hemisphere re-presents what has been seen. This discussion of cerebral neuroscience may seem irrelevant here but the connection lies with how Goethe's concept of the Urphenomenon continues to inspire modern thought and

interpretations. When Jane and I first met and she described her research and understanding of binary synthesis, I became interested in Goethean science. In particular the interpretation of Goethe's scientific studies of nature where "Goethe's mode of understanding sees the part in light of the whole, fostering a way of science which dwells in nature (Bortoft, 1996: 4).

## **2.4    *Summary***

In this second part of the literature review, I have endeavoured to give a flavour of German Idealism, Schiller's theory of aesthetic education and Goethe's concept of the primal phenomenon. I will evince in the later chapters of this thesis that it was Jane's deep understanding of this particular aspect of 18th century German philosophy that provided the spiritual foundation from which she could understand and endure the vicissitudes of her illness.

## 3 Methodology

### 3.1 Introduction

The research question for this study was stated in Section 1.7 as:

What can be learnt from a shared experience of living with and through a life-limiting illness?

This chapter details the research design and methodology used to address this question. It starts with an overview of the design and its relationship to the three subsequent sections: ethical considerations, theoretical framework and methods. These parts are consistent with the outline of a contemplative approach given in chapter one and its guiding themes of heart, head and hand. The rationale for locating the ethical dimension to the study at the start is also intended to address concerns arising from the identity of the central characters being explicitly revealed at the outset. The theoretical framework takes stories of illness as a narrative genre and starting point for the subsequent discussion. The final section on methods provides an account of the practical processes used in the study.

### 3.2 Research Design

In chapter one, I introduced this study as the personal account of the experience of caring for my dying partner and set out the structure of this thesis as a triadic framework. The research was designed to investigate the experience I had shared with my late partner of her illness from advanced cancer and her dying. The purpose was to establish if there were any aspects of her knowledge of 18th century German Idealism that had any impact on her demeanour during that time, the Illness Period. Without going into any detail I struggled throughout the study with the relationship between the experience of my partner's dying and the research methodology. I actively avoided committing to any particular approach believing that as the study was essentially a form of narrative inquiry (Riessman, 2008) the rest would follow when needed. But I was confusing narrative inquiry as a field of study (MacLaren, 2014) with the necessarily precise account of why and how the research was done. My resistance had many strands but centred on the role of Schiller's *Aesthetic Letter's* and binary synthesis in the study. I could not reconcile my 'felt-sense' (Gendlin, 2004) that the approach must have something to do with this obscure methodological tool. Yet I was also aware that this study could not be driven by some intellectual whim or trying to emulate Jane's doctoral work.

The resolution to the tension between what I wanted to study and how it could be done was found by tracing a convoluted path forward through the human sciences to a phenomenology of practice (van Manen, 2014) and then back through the later philosophy of Heidegger to Goethe and the Urphenomenon. The approach used here had many influences but the focus was sharpened by Heidegger's distinction between contemplative thinking as receptive yet meditative awareness, and calculative thinking that is "always on the move" and merely 'doing' an existing pattern of organized thought" (Galvin & Todres, 2007: 39). This 'letting be' opens up creative possibilities for "feeling, thinking and doing" (Galvin & Todres, 2007: 33) as a seamless integration of heart, head and hand. Viewed in this way, the research design has integrated the desire to act in the right way (heart) in consideration of the underlying philosophies (head) and then act appropriately with regard to the data collection and analysis (hand). The research design is summarised thus:

- Determine temporal and spatial boundaries
- Identify participants and their roles
- Identify data sources and access requirements
- Gather and organise data
- Analyse data as written inquiry

In the next section I will address the ethical aspects of the study before moving to the theoretical dimensions and concluding with details of the methods used.

### **3.3 *Ethical Considerations***

The opening paragraph of this thesis alerts the reader to some potential ethical issues: the subject is deceased, the researcher was their partner and there is no tangible evidence of consent. Taking an open and honest stance from the beginning is indicative of a genuine concern that this study should be consistently ethically grounded. By that I mean that all decisions and choices regarding the design and implementation of this study have been underpinned by ethical standards similar to those I have used for the past 15 years as an independent educational consultant. Quality is implicit in the sense that work is characterised by good practice:

- act with diligence, honesty, integrity and professional impartiality, without discrimination

- observe due care, objectivity and respect for confidentiality
- be explicit, frank and sincere in working with others
- be sensitive to the needs of others
- accept responsibility for this work and the effective use of resources
- encourage the development of others by sharing research, expertise and good practice while acknowledging the work of others

Ethical awareness, as the heart in the study, was ensured by using continuous consent (Allmark et al, 2009) where those engaged in the research reaffirm their commitment to continue. This did not just apply to the self-directed interviews but also to my own relationship with the study. There were occasions when I did question the wisdom of continuing with the personal nature of the study.

However, this is just the basis for the ethical considerations in this study. In general terms, they are focussed on two areas: research practice and the process of knowledge construction. The former is addressed through conformance with institutional and disciplinary policies and guidelines, while consideration of the latter in respect of narrative inquiry can raise issues such as authenticity and exploitation (Plummer, 2001). Ethics are the application of a set of moral principles to a given situation. In the humanities, the most common ethical research issue is gaining access to people, representative of a group of interest, as research subjects. These principles may represent an ideal standard of good practice to which researchers should adhere.

Research in health settings has particular sensitivities as respondents may be unwell, vulnerable and/or unable to give informed consent to their participation in a study. It is therefore not surprising that there may be other agencies who have a moral and legal responsibility to ensure safety through the minimisation of risk to both the potential research subject and the researcher. Initially for this study, ethical approval was only required from the university. However, when access to the health records was subsequently needed, ethical approval was sought and granted by both the health board and the NHS research and development office.

Returning to the ethical issues of knowledge construction raises the issue of representation:

Narrative inquirers understand that a person's lived and told stories are who they are and who they are becoming and that these stories sustain them. This understanding shapes the necessity of negotiating research texts that



respectfully represent participants' lived and told stories. (Clandinin & Huber, 2010: 439)

However, if the subject of the inquiry is no longer alive, how does that then alter and affect the position and rights within the narrative? In an autoethnographic context, loss is a prevalent topic and in particular the death of an intimate other (Ellis, 2007). If a relational view is included in the appraisal of the ethical dimensions of a study, then some of the potential difficulties that might arise, can be addressed. For example those who choose to write about personal loss feel that "our stories about people who have died serve as memorials that keep our loved ones alive in our memories" (Ellis, 2007: 14). But this feeling may not be shared by other family members. The research subject who can no longer respond or defend the representation of themselves is also likely to be a member of a family, a work colleague or an individual known to others. These relational others may not recognise the representation of the person being made by the researcher. While a deceased person may no longer enjoy the same legal rights as the living (Ellis, 2007), nevertheless there is a moral obligation on the researcher not just to be respectful but to be considerate of the others who knew the person concerned. Clearly, there is an assumption that the identity of the research subject is known and while "strategies such as fictionalising and blurring identities and places" (Clandinin & Huber, 2010: 439) may be used to conceal, it is perhaps better to minimise the risk of causing upset by honouring known sensitivities.

Another interpretation of ethical issues in relation to the writing of the storied lives of others is the "crude listing of seven concerns" (Plummer, 2001: 216–24), summarised as:

- Ownership and intellectual property rights – who owns the life being studied?
- Confidentiality – how recognisable are the lives being studied?
- Honesty and the scandal of life stories – is this an accurate description of a real life?
- Deception – has the researcher hidden their identity?
- Exploitation – how is the subject rewarded for their participation on the study
- Informed consent – do subjects know they are involved in research and what it is about
- Hurt and harm – will the subjects be adversely affected by the research?

Would any of these criteria present a dilemma for this study? Early in this research I discussed with Jane's family my intention to undertake some work related to my experience of caring for

Jane. Furthermore, anyone who has known me in the last 15 years will probably also have known my late partner Jane, as we worked together through our own consultancy. Consequently, given the easy access to information via the internet, a simple search will reveal various details of our work, and to some extent our lives. In legal terms, I am the sole heritor of her estate. Morally, while our families are aware of my research and her consent to being a research subject, their identities must as far as possible be protected. It was also important to recognise my own vulnerabilities as the bereaved partner, in the early months of the study. With regard to anonymity, I have adopted the approach taken by Liz Stanley in her account of her mother's stroke and death "All names in this chapter, including those of institutions and wards and cities as well as persons, have been changed" (Stanley 1993b: 214). However, I am not using a pseudonym for Jane; her death is public knowledge and naming her is a conscious act of commemoration (Stanley & Wise 2006) as well as a way of keeping her memory alive (Ellis, 2007). While Stanley did change the names of the cities in the account cited above, I have not changed the names of the two cities in this study, Edinburgh and Glasgow. Both have a particular position and identity in the Scottish psyche which is in itself part of the story. This discussion has addressed broad issues but there are some specific points that require clarification regarding the data sources. The first is privacy, which should perhaps be an eighth concern for Plummer's (2001) list of concerns above. The second is the welfare of both the researcher as interview respondent, and the interviewer.

Issues of privacy arise in two respects, firstly in the context of material in the public domain. In a comprehensive review of unsolicited first-person illness narratives (O'Brien & Clark, 2010) it was noted that there is an assumption that if material such as blog posts is in the public domain, it is freely available for research without specific consent. With respect of internet data sources, the authors contend:

'Participants' require greater levels of protection privacy and confidentiality than 'authors'. This distinction should be reflected in the manner in which data are reported. Researchers should be aware that verbatim quotations can easily be traced to their internet source" (O'Brien & Clark, 2010: 1679).

For this study it is only Jane's blog that is in the public domain and she was aware of the privacy issues when she published her blog posts. But some of the personal data used in this study also involves me as either a subject in Jane's writing in the blog and her diary, or in my own diary entries. I have therefore limited the extent to which those self-referential materials can be used

and accessed by not digitising them as part of the data set set. Furthermore Jane's pink diary which contains the last things that she wrote is very personal to me. I could not envisage it being viewed or handled by others. It enabled me to feel a physical connectedness to Jane through her increasingly spidery handwriting as death drew near.

With regard to the self-directed interviews, it was important that neither party engaged in the interview process were harmed by the engagement. This issue was addressed by specific arrangements for both me as researcher-respondent and the interviewer. An additional factor to muddy the relationship was that the interviewer knows me personally and had also known Jane. She is an 'intimate insider' (Taylor, 2011), a role that can be advantageous but may also reshape the relationship. Nevertheless, the benefits for me to be interviewed by someone who was familiar with my situation and whom I trusted outweighed the possible negative aspects. These issues were not ignored and for the avoidance of doubt or ambiguity, a memorandum of understanding (MoU)<sup>30</sup> was used. This helped to ensure we were both clear of the terms of engagement and to underpin the relationship. The MoU was felt to be less formal than a legal contract but with sufficient weight to be taken seriously. As the interview relationship was viewed as a professional service, an appropriate fee was remunerated as part of the MoU.

Provision in respect of our welfare was addressed for me by first ensuring the interviews were conducted in an emotionally 'safe' place. Secondly my supervisors were aware of the dates of interviews and the sensitive nature of the research. They were able to offer support and further guidance if necessary. The relationship between the researcher-respondent and interviewer is similar to that found in counselling. The colleague who conducted the interviews is also a trained counsellor and therefore had her own supervision arrangements. These provided the means for her to be supported in both the ethical decision of being the interviewer and subsequently. In order not to compromise her professional position, I have not divulged her identity. The interviews were undertaken with both parties in open awareness of process consent (Ellis, 2007). The interviewer regularly asked if I was okay to continue and I knew I could ask to stop if necessary. Issues can arise with this model of consent, for example when participants are given partial information but then feel they must continue (Allmark et al, 2009).

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30 See *Appendix 3: Memorandum of Understanding*

### 3.4 Theoretical Framework

In this section the theories that support the methodological direction of the study are discussed. A defining characteristic of the process used to determine this framework has been the return enhanced as an interplay between the knowledge insights from the literature and how this felt in relation to the study. I now understand these feelings as a kind of ‘aesthetic phenomenology’ which is more concerned with texture than structure in its desire to “portray the lived ‘sensuous taste’ of what an experience may be and feel like” (Galvin & Todres, 2011: 525). When this approach is then used to report research findings, it has “the potential to transform the reader or audience in ways that good poetry does, in that it can move or touch us” (Galvin & Todres, 2011: 525). In other words, it is important that this thesis, as the principal product of this study, is engaging to read. For this reason, the framework is first located within the genre of fictional illness writing for its textural insights before moving to a consideration of narrative inquiry as a structuring device. In this way the direction of inquiry can be viewed as being towards a narrative purpose that gathers experiential accounts.

#### 3.4.1 Writing Illness

Fictional writing about illness, disease and dying has within its narrow genre well-known works such as Aleksandr Solzhenitsyn’s *Cancer Ward* (1968) and Gabriel Garcia Marquez’ *Love in the Time of Cholera* (1988). Both were preceded by the real masterwork (Byatt, 2005), Thomas Mann’s *The Magic Mountain* (2005), the first English translation being published in 1928. In essence the story is a protracted account over seven years of a young man’s experience of tuberculosis and his extended stay in a Swiss sanatorium. Appropriately, for the context here, Mann draws on Goethe in three distinct ways: firstly the novel is essentially pedagogical, a Bildungsroman intended to educate the central character, Hans Castorp, and follows a similar path to Goethe’s own Bildungsroman, *Wilhelm Meister* (Gesler, 2000). Secondly, one character, the scholar Herr Settembrini, makes regular quotations from Faust (Byatt, 2005). Finally, while writing the text and then within it, Mann drew heavily on Goethean science, integrating a compendium of scientific ideas from that time (Greenberg, 1985). Read in this way, a central theme of *The Magic Mountain* is the inextricable link between art and science, beauty and nature. What Mann really achieves in *The Magic Mountain* is his play with the nature of disease and its brutal realities in contrast with the positive aspects of disease and death as spiritual insights (Gesler, 2000). In this last aspect, Mann makes a firm connection back to German

Romanticism and therefore Goethe's literary work. In other political writings, Mann makes use of binary synthesis in a similar fashion to its first use by Goethe and Schiller (Bishop, 2005).

A bridge from fictional writing about illness to non-fiction can be found in works such as Virginia Woolf's *On Being Ill* and her mother, Julia Stephen's, *Notes from a Sick Room* (Woolf, 2012). The daughter writes of illness obliquely, as an aesthetic project that attempts to render the otherwise linearity of illness, as simultaneously "a heightened state of awareness that cannot be learned, perfected, or replicated by another" (Coates, 2012: 9). Woolf's essay repudiates Stephen's emphasis on the 'art of nursing' in favour of the 'art of being ill' where illness is privileged with a vantage point from which to view the world (Coates, 2012). More recent illness writing may have lost some of Woolf's deep, philosophical insights but it is now a burgeoning field. Book length accounts of illness are rare before the 1900s and uncommon until after 1950 (Hawkins, 1993). Then from the 1960s onwards there is a steady rise in pathographies, "a form of autobiography or biography that describes personal experience of illness, treatment and sometimes both" (Hawkins, 1993: 1). Within this genre, if works are categorised by authorial intent, early examples are largely testimonies to the strength of the sufferer and their positive disposition towards the medical profession. Towards the end of the 1970s there is a dramatic change and a split into two distinct and opposing types of pathography. In the first, the authorial intent comes from "a sense of outrage over particular and concrete instances of what is perceived to be the failure of medicine to care adequately for the ill" (Hawkins, 1993: 6). In contrast, the second type is less at odds with the vagaries of modern medicine and speaks to "a patient population empowered by a belief in the near limitless capacities of the mind and the emotions to facilitate healing" (Hawkins, 1993: 9). Whatever the type, I suggest the purpose of these narratives is twofold: heroic recognition in the battle against either disease and/or the medical profession, and as an intentionally helpful travel guide through the strange and unfamiliar landscape of illness.

Bingley et al (2006) undertook a comprehensive review and content analysis of stories written by people with life-limiting disease in the past fifty years. Like Hawkins (1993), the authors found that in the 1950s there were few such accounts and they were invariably written by those with some formal knowledge of writing such as journalists, writers and academics. The longstanding tradition of poetry about death and dying was also acknowledged. More importantly they noted the huge shift that has occurred since the arrival of the internet and the consequent ease of informal publishing. Furthermore, from the 1970s the stories shifted from being about suffering

from cancer to “dying-of-cancer” (Bingley et al, 2006: 185). Their analysis acknowledges that writing about impending death is more complex than my simplistic interpretation above. Three perspectives are suggested:

- the act of narrative writing is therapeutic; its purpose is to organize and make sense of traumatic experiences;
- the content of the narrative is written as a description of a therapeutic and ‘witnessed’ journey;
- there are underlying motives to writing a narrative about facing death: creating new identity, continuity of self (Bingley et al, 2006: 191).

These interpretations are in relation to the perspective of someone with personal experience of life-limiting illness, but they may also be applicable to the partner of the ill person. In this sense they have personal relevance and the need for sense-making.

### **3.4.2 Finding Edges**

The first task in the research design is to determine the temporal or spatial boundaries. Locating these edges is essential for the recognition of what lies within the diffuse landscape of the study and equally what remains beyond its boundary. Inevitably some of the edges may be fuzzy, eroded by particular tensions leaving them barely discernible. Yet it is at these edges that important insights can occur. Feeling for the edge and letting it arise naturally from within allows meaning to move from being constructed to being embodied. Writing illness in this ‘felt-sense’ (Gendlin, 2004) accords with aesthetic phenomenology as ‘embodied relational understanding’ (Todres, 2008), defined as:

Embodied relational understanding refers to a way of knowing that is holistically contextual, that is, a form of knowledge that is attentive to the rich and moving flow of individuals lives in relation to others, is attentive to very specific situations, and to the inner worlds of what it is like for patients to ‘go through something’. (Galvin & Todres, 2011: 523)

Drawing the lines around the study helps the ethical process by providing and maintaining the temporal timeline of when, the spatial boundary of where and the personal/social boundary of whom. The relevance of inner boundaries may also become apparent for example during a clinical discussion between health professionals, “an oral performance in which the boundaries

between speaker and spectator blur, and control over the meaning is not clearly held by any one person” (Mattingly, 1998: 282).

Conventionally studies of cancer and palliative care experiences for both patients and carers have relied primarily but not exclusively on interviews (Thomas, 2009; Jack & O’Brien, 2010; Kendall et al, 2010; Payne, 2010) or diaries (Campion-Smith et al, 2011). A defining characteristic of this group is that they are all researcher-led. The studies set out to answer a specific question about the nature of the experience of the sufferer and, where included, their primary carer. Other studies have capitalised on existing narratives, particularly blogs (Bingley et al, 2006; Heilferty, 2009; Kim, 2009; O’Brien & Clark, 2010). In this group, the person with the illness experience is the initiator of the narrative, normally with therapeutic or existential purposes (Bingley et al, 2006;). Psychological studies that use standard questionnaire instruments to gauge anxiety or some other measurable feature of the person’s experience (see George 2002; Yao et al 2007) were discounted as not being pertinent to an understanding of everyday life in a social context.

In this study, there are definable start and end points delineated by diagnosis and death. There are other boundaries here; Langellier (2003) sees personal narrative as a liminal or boundary state, a place of transition between the personal and the public. Froggatt (1997) extends the concept of liminality in her study of hospice work finding it a state of transition for both the dying and the bereaved. For this study, both views are relevant. There are boundaries around what can be shared for public consumption and there is the temporal boundary of the shared experience. The related concepts of boundedness as bodily deterioration (Lawton 1998) and the forced embodiment of sickness (Skott 2002) may also be pertinent. Having considered some interpretations and configurations of the boundaries that might be relevant to this study, the need to make sense of what had happened as a whole, from the beginning (diagnosis) to the end (death) became apparent. This could be resolved using a sequence of time-ordered stories connected by a process of inquiry through writing (Richardson, 2000), that would lead to understanding.

### **3.4.3 Finding Meaning**

Boundaries can also help to determine meaning. According to Heidegger, we are practically engaged with our lifeworld through sensation and in such a way that any encounter comes with meaning and significance (van Manen, 2007). For example, looking at a timepiece it is not

simply an optical sensation but usually involves a question ‘how long until lunch?’ or ‘when will ...’. It is therefore in the “context of meaning in which our practices are embedded” (van Manen, 2007). We understand the world through our own way of being in the world which is informed by our cultural understandings and experiences. Heidegger’s perspective is ontological, a theory of being. It connects with the human desire to see living form as part of a greater whole, as a movement towards “coming into-Being” (Shotter, 2000: 234). Drawing on Goethe’s phenomenological methods, this living form can be interpreted as one which:

... instead of seeking to explain a present activity in terms of the past, we can understand it in terms of its meaning for us, that is, in terms of our spontaneous responses to it. It is only from within our involvements with other living things that this kind of meaningful, responsive understanding becomes available to us. (Shotter, 2000: 234)

It can be argued that a holistic understanding of narrative is one that conflates both ontology and epistemology, as a theory of knowledge, with no discernible space between knowledge and action (Butler-Kisber, 2010). This accords with Goethe’s view from his Bildungsroman, *Wilhelm Meister* first published in 1821:

Thinking and doing, doing and thinking, that is the sum total of all wisdom, recognised of old, practised of old, not realised by everybody. Like breathing in and breathing out, both are eternally moving backwards and forwards in perpetual motion: like question and answer, the one cannot really happen without the other. (Plenderleith,<sup>31</sup> 2000: 1)

These apparent polar opposites of thinking and doing can only make sense in relation to one another, especially in a narrative context; without one, the other fails to function. The implied rhythm also has a tempo, a timeline along which the interplay occurs, a narrative thread. Stanley (1992) in her study of biography, states that “The autobiographical archetype is Bildungsroman, the tale of the progressive travelling of a life from troubled or stifled beginnings; in which obstacles are overcome and the true self actualised or revealed” (Stanley, 1992: 11). Can the genre of Bildungsroman serve as example of the ontological-epistemological collapse characteristic of new paradigm thinkers (Guba & Lincoln, 2005)? Returning to insights from German Idealism provides a contrasting definition of Bildungsroman “issues are framed less in

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31 There is an added weight to this translation as it comes from Jane’s personal papers. Perhaps academia is inclined to fall into a Cartesian trap in its desire to separate ontology from epistemology; one cannot really exist, even in a philosophical sense, without the other.



terms of practicality (of which the realist novel speaks) than with a view to a philosophically differentiated definition and exploration of the interplay of self and world” (Swales, 2002: 143).

It is not proposed that this thesis is itself a Bildungsroman or that it contains one, as others have done (Jacobs, 2008; Knowles & Promislow, 2008), but it has helped inform the underlying philosophy driving the research. In an ontological-epistemological sense this is the analytic account of troubled lives where obstacles are overcome and the authentic self (of the carer/researcher/writer) becomes actualised. Liz Stanley kept a research diary as an exercise in ‘intellectual autobiography’ where she explored her attempts to make sense of her mother’s self following a stroke and summarises the process thus:

I have also used these diary extracts to construct a narrative – to ‘tell a story’ – around a set of ontological problematics (what did all this mean, regarding my mother’s self, regarding myself, regarding selves and consciousness in general) with epistemological consequentiality (what did all this entail for how I, we, understand what it is to have knowledge about another person, about one’s self). (Stanley, 1993b: 211)

The act of writing is in itself transformative just as the narration by clients as processes of remembering and retelling, are key elements in counselling and psychotherapy conversations (Riessman & Speedy, 2007). There is no single, true meaning to be found within this study. There are as many meanings, understandings and interpretations as there are readers; each will see it as part of a greater whole as it comes into being.

#### **3.4.4 Recognising the Narrative Turn**

Story telling is a defining characteristic of human behaviour; no other mammal has the language to tell stories. Stories imbue all aspects of our lives from the very private inner workings of the stories we tell ourselves to the public accounts of our behaviour and actions. The idea of using narrative in the social sciences began in the 1960s, gathering momentum to the extent that it is now everywhere, in every discipline, every profession (Riessman & Speedy, 2007). The narrative turn has become well recognised in the social sciences (Plummer, 2001; Riessman, 2008; Butler-Kisber, 2010) with each discipline having its nuanced interpretations and refinements. The turn can be traced historically through three distinct disciplines: literary theory, socio-linguistics and anthropology. Czarniawska (2004: 2) references Polkinghorne’s analysis of literary traditions through four national perspectives: Russian formalism (Mikhail Bakhtin), US new criticism (Northrop Frye and Robert Scholes), French structuralism (Tzvetan Todorov and Roland

Barthes), and German hermeneutics (Gadamer). Narrative, using Labov and Waletzky's (1997) socio-linguistic terms on two levels, clause and structure, is defined as:

First, fixed referential clauses, recapitulating in temporal order, 'what happened' correspond to narrative (ie, the narrated event, the 'told', the enhancement of experience); and free evaluative clauses answering 'so what's the point?' correspond roughly to the personal, the attitude of the narrator toward the incident, its significance, (ie, the narrative event, the 'telling', positioning, and identity). Second, a fully developed narrative has six structural components: abstract, orientation, complicating action, evaluation, resolution, and coda. (Langellier, 2001: 700)

Inevitably such a clear method for deconstructing complex texts has been widely adopted by narrative researchers, for example in studies of the biographical disruption of divorce (Riessman, 1990) and in the aftermath of trauma (Patterson, 2000). Finally and perhaps the most persuasive use of narrative has come from anthropology where Turner's study of ritual (1969) and Bruner's more recent insights of his earlier work with Native Americans (1986) have added to the scholarly interpretation and understanding of stories.

### 3.4.5 Narrative Inquiry

Framing research as narrative has been defined as allowing the researcher "to see different and sometimes contradictory layers of meaning, to bring them into useful dialogue with each other, and to understand more about individual and social change" (Squire et al, 2008: 1). But what is narrative itself and is it synonymous with story? The linguistic origins are different and therefore give some clue to more nuanced interpretations. The word *narrative* is a compound adjective or noun from narrate plus the suffix -ive, both derived from the Latin, *gnarus* or knowing with a descriptive quality or nature (SOED, 2007) while story is also from Latin, *historia* – history. As Frank has commented, the terms are often used interchangeably yet "people do not tell narratives, they tell stories" (Frank, 2000: 354). Riessman and Speedy distinguish narrative from other forms of discourse through the use of sequence and consequence within the narrative structure where "Events are selected, organized, connected, and evaluated as meaningful for a particular audience" (Riessman & Speedy, 2007: 430). However, both story and discourse can be seen as elements of narrative and can include the action of telling. In this configuration, a story is an abstract sequence of events while discourse is text in a particular medium or form, and telling is the act of narrating that produces the story (Bruner, 1986).

In general terms, researchers who engage in narrative inquiry find no difficulty in distinguishing between the phenomenon that is the story and the act of inquiry as the narrative, as “people by nature lead storied lives and tell stories of those lives, whereas narrative researchers describe such lives, collect and tell stories of them, and write narratives of experience” (Connelly & Clandinin, 1991: 2). However, this clarity may have become smudged as it has been suggested that there is a fault-line which “concerns ‘narrative studies’ (signalling a focus on narrative as a particular kind of data or the content of this) as compared with ‘narrative inquiry’ (signalling narrative as a methodological and analytical approach by the researcher)” (Stanley & Temple, 2008: 276).

Definitions of narrative inquiry are likely to be dependent on the parent discipline with nuanced different positions between sociologists, psychologists and educationalists. A simple interpretation that resonates with this study is “narrative inquiry is a way of understanding experience” (Clandinin & Connelly 2000: 20). Their approach centres on the collection of ‘field texts’ which are ‘composed’ and are what “passes for data in narrative inquiry” (Clandinin & Connelly 2000: 93). These texts can range from existing artefacts and include journal entries, field notes and research interview transcripts. Analysis is facilitated by appropriate archival processes to store the field texts, usually in chronological order. For this study two types of field text are used: documentary material and self-directed interviews. While the method for the latter is discussed in Section 3.5.1.2, the techniques on which it drew are detailed here. The basis for the pre-existing material is drawn from the approach suggested in *Documents of Life* (Plummer, 2001). This is concerned with telling life stories from a critically human perspective by drawing on personal narrative augmented by other documentary data from life. These documents can range through:

- personal: diaries, letters, email, interview transcripts
- public: blog postings, social media posts
- official: certificates of birth, marriage, death; hospital correspondence, policy documents
- visual: diagrams, maps, photographs

How they are used, analysed and framed is for the researcher to determine; Plummer (2001) offers a wealth of practical advice and guidance for researchers wishing to use such sources. More recently a further aspect has been noted:

Letters and correspondences are everyday documents of life strongly

characterised by seriality and succession – their ‘one thing after another’ temporal aspect – and consequently they provide, not only a humanly rich data-source, but one particularly suitable for investigating changes over time. (Stanley 2012: 2)

Returning to the ordered field texts, an iterative process is used as the researcher-writer shuttles back and forth, weaving the emergent research text into a cloth that can be shaped and tailored through editing to fit the intended purpose. The energy and enthusiasm for narrative inquiry, and the eagerness to engage with its complex and nuanced storied experiences is compelling (Clandinin & Roseik, 2007). Despite the difficulties of writing in this way, narrative inquiry is seductive in its prospect of novel and innovative possibilities. There is nothing inherently wrong with more conventional approaches that examine through thematic analysis ‘what’ is said in the content a story, and through structural analysis ‘how’ it said or organised (Riessman 2008). Yet even when told in this way, these stories continue to speak to us (van Manen, 2006), to find their real meaning (Sharp, 1996) perhaps hoping to become ‘thrice told tales’ (Riessman 2004).

#### **3.4.6 Biographical Approaches**

Recognising the serial nature of the narrative from the Illness Period as one which unfolds over time and has a chronological sequence, I turned to life story (Atkinson, 2007) and biographical interview methods (Bornat, 2008; Jones, 2003) to inform the approach to the self-directed interviews. Each method aims to capture an individual’s life story but they differ in process. Atkinson’s approach is cross-disciplinary and he provides over 200 potential questions from which the interviewer can draw a personal subset (Atkinson, 1998). By contrast the biographical narrative interview method (BNIM) makes little use of interrogative structure and begins with the simple question “I would like you to tell me your life story, all the events and experiences which were important to you” (Wengraf, 2001: 119). The respondent is allowed to speak freely and without interruption. BNIM has been interpreted and used, for example, to study fear of crime (Hollway & Jefferson, 2008) and identity in the informal care role (Jones, 2001). An essential feature of biographical methods is that “accounts are solicited and told in the first person” (Bornat: 2008: 344). However, none of these methodological accounts and guidelines address the issue of the known subject. Conventionally, research subjects or ‘ordinary people’ (Wengraf, 2000: 140) are recruited through third parties such as organisational settings or from somewhere the target group are known to congregate. Consequently, those who are co-opted to the study are unlikely to be known to the researcher; indeed if they are known they will be

discounted by the study's exclusion criteria. This tradition is seen to have many benefits including the anonymity of the research subjects and conformity to ethical research standards.

There are two caveats though, regarding the extent to which what a respondent says in an interview can be regarded as an authentic account. The first concerns the natural tendency of the narrating subject to withhold aspects of their story that will be upsetting to them in their recollections; a subconscious defence against anxiety (Hollway & Jefferson, 2008). The second issue is an extension of this point and relates to the interviewer who may also subconsciously defend themselves against anxiety. This "motivation not to know" (Wengraf, 2000: 144) may then subtly influence the course and direction of the interview. It has been suggested that these issues can be mitigated by using BNIM with its minimalist interview schedule and enhanced with the additional techniques of free-association and gestalt (Hollway & Jefferson, 2008). In effect, the respondent can speak freely without fear of interruption and the researcher is not compromised by their own feelings.

What is evident from any of these approaches to biographical interviews, is that there are two roles involved, a research interviewer and a research subject, and they are not conflated. The interview participants may even be engaged in a conversation (Kvale, 2007) or in a novel, interactive process of discovery (Ellis et al, 2011). If the primary focus of the research is to explore a personal experience then the most common approach to capturing that testimony is simply to write it as a personal narrative (Langellier, 1999) or as an autoethnographic account (Ellis & Bochner, 2000; Ellis et al, 2011). Self-interview techniques were investigated where respondents use a voice recorder to capture their reflections on a specific topic, possibly in response to a stimulus such as a photograph or artefact (Allett et al, 2011). This can be advantageous as it allows the self-interviewee to pause and reflect on their recollections and memories. But this self-reflection could also result in filtering by the respondent of difficult or sensitive areas in a manner similar to that suggested by Wengraf (2000) as motivation not to remember. If an interviewer is present, problematic areas can be explored within the constraints outlined above. Auto-interviewing (Boufoy-Bastick, 2004) which utilises similar techniques as those for self-interview was also explored. However, the purpose has a more anthropological slant as it attempts to surface culturally embedded worldviews of 'epic reporting' Boufoy-Bastick, 2004: 3) a process which utilises the 'thick description' (Geertz, 1973) of visual memories. This approach was near to my purpose but the cultural focus was too broad. Realising there was no

‘perfect’ method to elicit my recollections of the Illness Period, I decided to develop the self-directed interview method.<sup>32</sup>

### 3.4.7 Quality in Narrative Inquiry

In the context of qualitative research, framing practice in terms of validity and reliability risks locating the study “within a modernist, scientific paradigm” (Seale, 2000: 98) which is only one of several available approaches. But that was my familiar place for locating quality and is not necessarily invalid or inappropriate. An indicator of methodological awareness as a ‘craft skill’ should take as its starting point a “positivist discussion of measurement validity, internal and external validity, reliability and replicability” (Seale, 2000: 102) despite the contentious nature of these issues (see Kirk & Miller, 1986, Morse, et al 2002). Concerns regarding objectivity may also be raised to add further controversy in the subjective world of narrative inquiry. The study of an individual further compounds matters as a single case cannot look to generalisation as a source of validity (Thomas 2011). The traditional views of “the concepts of validity, reliability, and generalisation have obtained the status of a scientific holy trinity” (Kvale, 2002: 300). Consequently, in the postmodern world of multiple truths and multiple ways of knowing, these views necessitate alternative interpretations. Kvale argues for a rejection of the abstract, philosophical understanding of validity in favour of the credible researcher crafting their research, perhaps echoing the “researcher-as-bricoleur and quilt-maker” (Denzin & Lincoln, 2000: 4). His is a “pragmatic validity” (Kvale, 2002: 316) of verification, a view shared by Morse et al (2002) who claim that by using the language of science, the validity of qualitative research will be recognisable. They further contend that rigour has largely been replaced by evaluation criteria for “the overall significance, relevance, impact, and utility of completed research” (Morse et al, 2002: 14). Explicit in the quotation is the emphasis on research that has finished and therefore summatively evaluated. They propose a return to rigour through the use of verification strategies that are employed throughout a study to monitor the validity and reliability of the research process.

Alternatively, these tensions can be addressed by using an approach similar to that for ethics, one of continual quality awareness. This is to recognise the range of existing techniques and identify those most appropriate to a particular study (Seale & Silverman, 1997). Circumspection and caution are also needed to avoid adopting a mechanistic, checklist approach resulting in “the tail

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32 Credit is due in part to the interviewer for the idea as it emerged in discussion with her.

wagging the dog” (Barbour, 2001: 1115) or an instance of calculative thinking at the expense of a more contemplative attitude. For some (Meyrick, 2006) quality is synonymous with rigour or at least as a means of ensuring quality is built in to each stage. Two suggested characteristics of a quality framework, in the context of health research, are first that it is transparent, that is any change in focus is justified. Secondly, that it is systematic, demonstrated by the use of an analytic framework or in describing processes (Meyrick, 2006). However, in the borderlands of narrative inquiry (Clandinin & Roseik, 2007) such strategies may continue to appear overly prescriptive.

While I have no difficulty in accepting that in the postmodern world, traditional positivist approaches are not wholly relevant to narrative inquiry, I agree with Seale (2000) that they can provide a useful place to start. If reliability is applicable to consistency and technique, and validity is about ensuring the technique is doing what is intended (Plummer, 2001) then that seems to be similar to being systematic. However, I suspect it is a question of degree or extent: while it may seem relatively easy to consistently apply the same technique, the reality is that every interview will be different despite an apparently identical instrument. What matters then, is that these issues are recognised and mitigated in a realistic and reasonable manner. In the context of this study, there are other potential concerns with the more prosaic matters of bias and memory (Plummer, 2001). Inevitably there is bias in this work as the rosy side of life is recounted in the full face of adversity. There is no way to prove the authenticity or otherwise of the narrative. However, there is a desire to give an accurate account as evidenced by the use of other data sources. We know our memories can play tricks on us as we selectively remember the good bits while discarding those less choice. Traumatic experience (Caruth, 1995) also affects what can be remembered and then spoken. Memory is not a simple act of recalling things past but a complex interplay of episodic and semantic recollections (Klein, 2012). For example, episodic memory is referenced to access an answer to the question, ‘where were you last Tuesday?’, but it is semantic memory that knows we were born despite having no recollection of the event.

Narrative research must rely on other devices to have some surety of its claims. Taking a pragmatic approach, an awareness of coherence, persuasiveness and presentation (Riessman, 2008) can add weight to the authenticity of the narrative. The story needs to be believable, told in a convincing manner and presented in a style appropriate for its audience. When asked by a student what validity meant for her, Carolyn Ellis replied that it:

... means that our work seeks verisimilitude; it evokes in readers a feeling that the experience described is lifelike, believable, and possible. You might also judge validity by whether it helps readers communicate with others different from themselves, or offers a way to improve the lives of participants and readers or even your own. (Ellis & Bochner, 2000: 751)

Notwithstanding the comments above that narrative inquiry, by its very nature must seek alternatives to attest its validity, there are interpretations of conventional practices which can be used. Generalisability is one example of how this issue can be addressed in life history research and documentary analysis. Payne and Williams (2005) favour a form of intermediate or moderatum generalisation in two senses. Firstly, the scope of any claim should be moderate and secondly, with a view that is open to change (Payne & Williams, 2005: 297). Furthermore, the research design should facilitate the conscious production of such generalisations; making the strange familiar. The more complex issue of how we can know what we know can be addressed by understanding the position of the narrated subject both inside and outside the narrative (Doucet & Mauthner, 2008). This may necessitate more than 'reading against the grain' as a method of re-reading which "insists that all texts, whether 'primary' or 'secondary', published or unpublished, should be subject to ongoing re-interpretation and re-evaluation in light of changing reading contexts" (Dampier, 2008: 375). Instead the Listening Guide (Doucet & Mauthner, 2008: 405), can be used to read the text four times to elicit:

- what is happening in the narrative;
- use of the first person;
- relations to the subject;
- any identifiable power relations or dominant ideological structures.

However, familiarity with the principal subject has again negated unbiased use of these techniques but an awareness of them was helpful when writing the analytic narrative in Part Two. Whatever techniques are employed to assist in the process of re-reading, the authors cited above do not mention the temporal dimension. Perhaps this should be obvious to the researcher but nevertheless methods such as the Listening Guide involves distinct processes that will generate different interpretations and nuances at different times. When using re-reading techniques in this study, allowing some time to pass between readings, such as a few weeks, helped to see things differently and to realise that other interpretations could be made.



From the foregoing, the quality criteria that seem most relevant to this study are that it is rigorous, reliable, transparent and systematic. To that I would also add aesthetic as the “sensibilities that play such a key role in evaluating objects of any kind, whether consumer goods, works of art or works of science” (Sandelowski, 2015: 86). Implicit in this description is that it is an ‘individualised assessment’ (Ravenek & Rudman, 2013), typical in qualitative research which is reported in highly variable styles and not standardised scientific reports (Sandelowski & Barroso, 2002). But this is more than recognition of the difference between the form and content of a research report, it is another ‘craft skill’ altogether: one that recognises the intersubjectivity between the researcher/writer and the reader, and the feeling evoked through the aesthetic quality of language that is central to understanding (Todres & Galvin, 2008). This is writing aesthetic phenomenology in a way that by “researchers first going through a process that enlivens the phenomenon for them, it is more likely that readers can engage with the results of this more evocative offering in new and emotionally receptive ways” (Todres & Galvin, 2008: 577).

### 3.4.8 Narrative Inquiry in Practice

The theoretical considerations conclude with an overview of Clandinin and Connolly’s (2000) three dimensional narrative inquiry space, the framework used to ensure that the approach to the analytic narrative was reliable, transparent and systematic. It is based on Dewey’s experiential philosophy and utilises a metaphorical structure in which any particular narrative inquiry can be defined as an intersection between:

- temporality or continuity (past, present, future)
- interaction (personal, social)
- situation (place)

Within these dimensions the narrative inquirer moves in different directions: inwards, outwards, backwards and forwards. The purpose is to explore “life as it is experienced on a continuum” (Clandinin & Connolly, 2000: 19). This sense of movement as travel appears in other descriptions of narrative “Travelling back and forth, revisiting the old sites of memory and significance, reshaping the past and future – isn’t that precisely the kind of travelling that narrative is all about?” (Hyvärinen, 2006: 9). Similarly, Hermans emphasises not just temporality but draws on Bakhtin in acknowledging the spatial dimension of narrative:

... time and space are seen as equally important for the narrative structure of the dialogical self. The spatial nature of the self is expressed in the words 'position' and 'positioning', terms that suggest, moreover, more dynamic and flexible referents than the traditional term 'role'. (Hermans, 2001: 249)

The quotation suggests that travelling back and forth through the data is not simply concerned with who was doing what and when, but also the position of the individual at a space/time intersection. In their approach to narrative inquiry Clandinin and Connelly (2000) emphasise throughout the need for the inquirer to maintain a continual awareness of the interaction, continuity and situation within the narrative. The researcher reading a text is simultaneously aware of three dimensions: the temporality of past, present and future; the interaction between people and events; and the place or space where the action is located. This sense of movement can now be carried forward to writing when "we may go back and forth a number of times until we get a feeling of aesthetic satisfaction that the words are good enough to carry forward the aliveness of the meanings" (Todres & Galvin, 2008: 577).

### 3.5 Methods

This section details the processes used to collect and analyse the data for the study. The steps outlined in the research design concerned identifying and accessing the participants and data, collecting and organising the data and then analysing the data through a process of written inquiry. These are addressed in two subsections, data collection and data analysis.

#### 3.5.1 Data Collection

In order to gather the data relevant for this study, the temporal and spatial boundaries were first determined. The Illness Period was defined as the time from my first becoming aware that Jane might be ill to her death. There was a specific incident when it occurred to me that Jane might be seriously ill and that became day one. Existing calendars and diaries were used to first create a spreadsheet time line as a chronological guide to the sequence of events during the Illness Period.<sup>33</sup> Precise dates are not used, only the month or day number are given. The duration of the Illness Period from day one to death is 342 days, approximately 11 months. The location of all events is central Scotland but no details are given of specific places. The action is mainly in Edinburgh which may add a sense of aesthetic as it is a beautiful place. The subject of study, my late partner Jane, is obviously not an active participant but as part of the ethical discussion in Section 3.2, my role and that of the interviewer can be considered as participatory. No other

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<sup>33</sup> See *Appendix 4: Illness Period Time Line*

persons, such as friends, family or health professionals were directly involved in the study. The role of the interviewer is detailed below in Section 3.5.1.2.

#### *3.5.1.1 Field Texts*

In temporal terms, there are two types of field text: pre-existing documents from the Illness Period and the interview transcripts created during the study. As the pre-existing documents informed the interview process, they are addressed here before the detailed description of the interview process in the next section. The pre-existing documents were either personal materials written primarily by me or Jane, or official documents such as hospital letters. Although consideration was given to accessing more detailed health records during the design process, it was decided in consultation with the study supervisors, that the need was not clear. However, as interview data collection progressed, the possibility of validating the factual aspects of the recollections against the health records emerged. The rationale was that an essential dimension to the overall story might be missed if the narrative account relied solely on personal documents. The justification and purpose was to verify the accuracy of events in the interview through reference to the historical account in the health records.

The actual process of gaining access to the health records took eight months of convoluted procedures. There were records in two different hospitals as well as those from primary health care, the general practitioner (GP) records. Despite all three care providers being within the same local health board and a unified ethical approval process, the reality was otherwise. Although access was applied for and granted by the NHS Research Ethics Committee, the primary care records required a different procedure. A further application had to be made to the practitioner services division within the health board. The decision to grant access was then passed to the GP practice who felt guidance was necessary from both the Medical Defence Union and the General Medical Council despite the assurances provided by the various approvals and my lead supervisor. Once these sensitivities had been addressed, I was able to access all of Jane's health records.

Following the guidance given for the preparation of field texts as a data archive (Clandinin & Connolly, 2000) the data were assembled. This involved converting them to digital format where necessary and cataloguing each item as a field text. All data were anonymised by redacting identifiable text and stored electronically in encrypted form. This was done within the terms of the university's policies and guidance regarding the security and protection of research data.

Where this was not technically possible and for all original documents, they are stored securely and remain in my ownership. All paper copies of non-personal items will be destroyed at the end of the study. The following table details the completed corpus, totalling 175 field texts:

Type	Total	Description
Blog posts <sup>34</sup>	35	Jane's own accounts from the Illness Period
Email correspondence	76	Personal email predominately written by me or by Jane but also including other family members
Storyboards <sup>35</sup>	11	Tabular interview guide with six cells, one for each selected event and for given episode period
Interview transcripts <sup>36</sup>	11	Prepared from the interview recordings, average length 58 minutes and ~7,400 words
Health records <sup>37</sup>	42	Predominately inter-professional correspondence but including operation notes and diagnostic reports

**Table 3.1 Field Texts**

All of these data have been organised both chronologically and by source against the Illness Period Time Line. For this study a process similar to the life history calendar (Freedman et al, 1988) was used where events are plotted over time.

### 3.5.1.2 Self-directed Interviews

Self-directed interviews were developed for this study, to facilitate the recollection of a series of episodes which may be traumatic to recall and therefore difficult for the inquiring researcher to undertake without assistance. Essential to the method are pre-existing documentary materials from the time period of interest, for example diaries, calendars or other materials such as email correspondence. An initial analysis is made to bound the time frame and to determine the main focus of the interviews. All of this is predicated on the discussions earlier in this chapter regarding the ethical considerations and quality criteria in use. The process is heart-felt not head-lead.

Selection of the interviewer is guided by the researcher finding someone with whom they feel comfortable and a basis for mutual trust. Typically, this would be a similar relationship to that with a counsellor; an interviewer with counselling skills is particularly advantageous. The researcher should also consider the support needs of the interviewer; a qualified counsellor is

<sup>34</sup> See *Appendix 5: Blog Post*

<sup>35</sup> See *Appendix 6: Storyboard*

<sup>36</sup> See *Appendix 7: Interview Transcript*

<sup>37</sup> See *Appendix 8: Hospital Letter*

likely to have their own supervision arrangements. If they do not, then while I do not consider it to be within the researcher's remit, they should at least advise the prospective interviewer that they may wish to make some provision for their own welfare. Ideally, the interview relationship should be seen as a professional service and therefore remunerated by an appropriate fee. To clarify roles and remit, and for the avoidance of doubt or ambiguity, a memorandum of understanding (MoU)<sup>38</sup> can be used.

The decision regarding the type of interview instrument to use lies with the researcher and could be a conventional topic guide or question schedule. However, in this study a separate storyboard for each interview was used. Storyboards are most commonly found in the creative industries where they give an overview of the scenes for a film, television show or advertisement and consist of a series of cells containing a visual depiction of each scene or frame (Cristiano, 2008). The concept was also informed by the biographical enquiry sources consulted which advocated an appreciation of chronological life history (Atkinson, 1998; Wengraf, 2000; Elliot, 2005) and from the use of visual stimuli as an aid to recollection (Allett et al, 2011; Boufoy-Bastick, 2004). In addition, the use of temporal memory aids such as event history calendars (Belli, 1998), life history calendars (Freedman, 1988) and life-grids (Bell, 2005) was reviewed.

The process of identifying, categorising and ordering the pre-existing field texts against the timeline had helped to identify the distinct episodes that would be the basis for each interview. The interviews were intended to each last approximately one hour and I calculated that if each storyboard had six cells with ten minutes worth of material that would be sufficient for an interview. The field texts were reviewed for suitable extracts such as what was happening to Jane, or in general at particular times. The principal materials used were calendar events, blog posts and personal diary entries. For some storyboards short extracts from email correspondence and hospital discharge letters were used. Each storyboard covered a particular episode of variable length and each had a title drawn from either the field texts or my recollections, as summarised in the following table:

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38 See *Appendix 3: Memorandum of Understanding*

Episode	Title	Duration in days
1	Something's wrong – feeling ill	21
2	Diagnosis – awful truth	8
3	Treatment – chemo babble	21
4	Taking responsibility	65
5	Still hopeful – out and about	80
6	Honest GP – best Christmas ever	39
7	Diagnostic nightmare	36
8	Shrinking life – swelling belly	18
9	Far flung friends	17
10	Breaking out of the hospice	18
11	The last dance	20

**Table 3.2 Storyboard Episodes**

Naming each episode had the immediate effect of framing its content. Once each storyboard was ready, it was sent to the interviewer for review and she then prepared her own schedule of questions<sup>39</sup>. The purpose of the interviews was that while I was very familiar with the overall story, I wanted the interviews to capture the fine detail and 'thick description' (Geertz, 1973) of particular events and episodes. The core brief for the interviewer was to find out what I actually observed Jane feeling or experiencing. So although I effectively became the research subject, the interviewer's paraphrasing of the storyboard was to ease conversation and did not alter the intent of the inquiry. It was also important that I did not rehearse before an interview. Although I was clearly defining and bounding the topics for each interview, I wanted them to be fresh.

The first interview, in July 2013, was used to pilot the process. We met at the interviewer's counselling rooms as a neutral place and to avoid being disturbed. All went according to plan with some minor adjustments and the remaining ten interviews were conducted between August and November 2013. Each interview was recorded and then transcribed by me using Express Scribe<sup>40</sup> transcription software. This has various features that facilitate the easy transfer from an audio format to text. The decision to do the transcription myself was not difficult as at the time I did not want anyone else to hear the recordings. I also felt some familiarity could be gained from the process despite its tedious nature. A tidy version of each transcript was extracted for analysis by taking Plummer's (2001:150) recommendation to adopt Finnegan's approach. That is to edit

<sup>39</sup> See *Appendix 6: Storyboard* for example with interview schedule

<sup>40</sup> <http://www.nch.com.au/scribe/index.html>

the transcript and remove hesitations, corrections, non-standard spellings and incorrect punctuation (Finnegan, 1992).

### 3.6 *Data Analysis*

The field texts were digitised with the intention of using data analysis software to assist with interpretation. MAXQDA was selected as the qualitative data analysis tool and while many universities appear to have a preference for NVivo, my impression is that is novice researchers learn to use it and then resist change to other comparable packages. In a comparison of both tools, MAXQDA was found to be preferable as it supported “the inter-relationship among the data, code and ... the ease of reaching and using memoing tools enhanced interaction with the data” (Kuş Saillard, 2011: 20). The user interface is clearly structured and divided into four windows enabling the document set, a specific text, the coding scheme and coded segments to be viewed simultaneously. This facilitates an intuitive approach to the qualitative data analysis process. The lexical search feature is also useful for cross-checking analytic interpretations and post-it style memos can be attached to both documents and codes. I have also used MAXQDA for many years and could therefore capitalise on my familiarity. The corpus was loaded into MAXQDA and the field texts organised into document types: blog posts, storyboards, medical records, and email.

Fortuitously at this time, I heard the Irish author, Bernard MacLaverty on BBC Radio 4 talking about his literary life (Open Book, 2013). He recounted how a school teacher had asked him to summarise his stories into a single word. It occurred to me that this might be a useful way of scaffolding the narrative. I was prompted to make a list of one word titles and noted them in my research journal. These titles are not the same as those used for the interview episodes and can therefore be interpreted as indicative of a transition from the ‘felt sense’ of my experience to one of ‘contemplative thinking’ as a return enhanced. The single word title helps to keep in focus what each episode is about as it is being written. Using MAXQDA as a document management system, each of the nine episodes were then collated as individual document sets using the chronological event sequence and the relevant field texts. This helped to focus on the particular story episode as a group in the document window of the software. The storyboards were also useful as reminders of what was originally considered relevant for each story within the overall narrative. The following table summarises the three epochs and aligns the stories within them:

Epoch	Months	Story	Description
Diagnosis	1 – 2	Wondering	What is wrong with Jane, why is her belly swollen?
	2	Finding	The tumour is seen in an ultrasound and then by the surgeon
	2	Planning	The oncologist's plan of campaign to attack the tumour
Plan B	2 – 3	Treating	The chemotherapy plan in action, also know as the great poisoning
	3 – 4	Turning	Everyday life dances around treatment sessions and hospital appointments
	5 – 7	Living	Still hopeful of successful treatment
Palliation	8 – 10	Reviewing	Christmas and the oncologist wants the surgeon to have another look
	11	Part[y]ing	Family and friends visit from near and far
	12	Dying	The last days as the dance fades out of her

**Table 3.3 Narrative Episodes**

Writing the analytic narrative then proceeded with reference to Table 3.3 and each storyboard using an iterative and connecting process. The narrative weaves between the two principal voices, mine from the interviews and Jane's from her blog posts, connected by an analytic thread. This does two things: first it makes the connections between the various texts and second, it turns to the literature to explain aspects of the story. This process illustrates the creative possibility, suggested at the start of this chapter, of "feeling, thinking and doing" (Galvin & Todres, 2007: 33). The intention was the seamless integration of feeling my way into the texts, then thinking about possible explanations for particular aspects before doing the writing, a continual process of heart, head and hand. The first drafts made extensive use of both interview and blog extracts; I did not have the heart to reduce them. Gradually, the quotations were reduced as the essence of each was found and a sense of aesthetic phenomenology began to emerge. But the process is deeper, an embodied interpretation in the making. Gendlin (2004) describes a bodily process of a 'felt-sense' coming into language as words like sleep or tears and "what comes in this way feels more deeply and uncensoredly from yourself than anything that you could construct" (Gendlin, 2004: 132). This is in the same philosophical place as Heidegger's coming into Being which reaches back to Goethe and the Urphenomenon. It is abiding with the feeling of the experience and waiting for it to come into words that are often surprising but also have that immediate sense of being the right ones.



### 3.7 *Summary*

In this chapter I have detailed the ethical considerations, the theoretical framework and the methods used in the design and conduct of this study. The overall approach described is contemplative and guided by the themes of heart, head and hand. Narrative inquiry as an approach for writing about lived experiences has been explored and detailed. The theoretical underpinnings for the methods have been identified and the research procedures used were thorough. Part One of this thesis has first set out the background for the study and its unusual dimensions. The literature to both the experience of illness and German Idealism was reviewed and the concept of binary synthesis introduced. Finally, the methodology has been described with aesthetic phenomenology as a contemplative narrative its central theme.

## Part Two: The Dance to Death

Having struggled with the *best* way to present the data and after many iterations, I arrived at an approach similar to that described in Section 3.4.2 as *embodied relational understanding* (Todres, 2008). In writing *The Dance to Death*, I have attempted a style of expression where “embodied interpretation is [used] to communicate findings in more evocative ways that may support readers in understanding, in an empathic way, what a phenomenon may be like” (Todres & Galvin, 2008: 580). The process can be considered a *return enhanced*<sup>41</sup> to the witness testimony of my experience now re-appreciated through understanding from the academic literature. This could also be expressed as an interaction between *heart* as experience and *head* as objective truth as enacted by *hand* through the research process. The purpose of Part Two of this thesis is to address the first three research questions<sup>42</sup>.

Ethical considerations are addressed by using only the month or day number for any of the pre-existing data while interview quotations as specific to the study are fully dated. In addition, all references to others are shown by their relationship or role in square brackets: [my sister], [the surgeon]. Some brief background to the Dance to Death is needed before the story proper. After ten hectic years of running our own educational consultancy we had grown weary with the effort and decided to embark on a new adventure. Our plan was for a quieter life in northern France, nearer to our mutual interests of food, wine, walking and cycling. Getting there was a huge undertaking that left us both exhausted, drained and trying to survive the winter in a small caravan with two grumpy cats and temperatures of  $-20^{\circ}\text{C}$ . After a month of cold angst, we abandoned the plan and made our way slowly back to Scotland. We stayed with family in Belgium to pass the two months required by quarantine regulations before our cats could re-enter the UK. As we had no permanent home, we headed for Glasgow and temporary lodgings with Jane’s mother. We could have chosen to live anywhere in Scotland but decide on a flat in Edinburgh with a decent garden and a view of the nearby hills.

## 4 Invitation to the Dance

### 4.1 Introduction

In this first chapter of Part Two, the analytic narrative as an embodied appreciation of the shared illness experience begins just before Jane’s diagnosis. The titles for the three episodes reflect the

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<sup>41</sup> See Section 2.3.3

<sup>42</sup> See Section 1.7

defining themes: Wondering, Finding, and Planning. Each episode has its own section but no subsections are used to avoid interrupting the narrative flow. The chapter details events over the first two months of the Illness Period, forty days in total. At approximately six weeks this is the shortest period covered in these three chapters.

## 4.2 *Wondering*

The first suggestion that Jane is not feeling as fit as she once had, comes in a blog posting where she reflects on a day's hill walking on Ben Lomond:

The views were splendid, if a little hazy, and I had a grand time to myself recognising old friends. The Cobbler and the rest of the Arrochar Alps, Ben More and Stob Binnein, Ben Lawers and 'that wee pointy bastard in the distance' which, as Muriel Gray memorably remarked, is always Schiehallion. There were cows and calves grazing near the path, butterworts, harebells and violets bright flashes of colour along the way, and the loch shining deep and blue below Ptarmigan ridge.

I thought I was fine in my new boots, striding up the path, sure-footed on the slight scrambly bits off the top, but boy did I suffer later. Thigh muscles so sore and tight that each normal walking step was painful for several days afterwards. So a few lessons learned. Mountain climbing in your 50s is not the same as mountain climbing in your 20s. The days of bouncing up and back down again in three hours or so are long gone. (Blog post 'Ben Lomond', day -10)<sup>43</sup>

This illustrates the essential Jane, someone who loved and knew the Scottish mountains, full of energy and enthusiasm for adventure yet innocently bemused by her apparently recalcitrant body. It also demonstrates her aesthetic appreciation of the scenery in terms of both the macro grandeur and the micro detail of particular wild flowers. I recall the walk in my first interview and the curious difference in our fitness:

When we were staying with her mum, Jane increasingly had this low back pain. I believed [it] was to do with tension and stress and that we could fix it by doing more exercises. But the hill walking, Jane was younger than me and had always been ahead on the hill, faster than me, more fearless, more gallous. But we seemed to be much more evenly matched and I really noticed that she did complain for days afterwards about how sore her legs were.

And then I think it was either one or two weeks later we did this long walk which was a bit easier going and it was a lovely walk but she she didn't have

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<sup>43</sup> Negative day number to indicate this is before the defined Illness Period.

the pace that she she had previously. But I didn't particularly notice that at the time, we were just enjoying the walk and pleased to have made the decision to be in Scotland and to have found the flat. (Interview 1, 9 July 2013)

These vague symptoms of low back pain and fatigue are typical of ovarian cancer, the 'silent killer' (McCorkle et al, 2003) that creeps insidiously hidden deep within its unsuspecting host. While I recognise and accept that I was in no way responsible for Jane's illness, I now wonder if there were two contrasting processes at work. The first is Gadamar's concept of a fusion of horizons and the second is the idea of a mutual conspiracy of silence (Zerubavel, 2006). Gadamer recognised that understanding in the present can only be achieved by acknowledging the prejudices of the past through a "the fusion of horizons" (Gadamer, 2004: 306). However, it is not simply the sense of a historical awareness of the past that matters. It is also coming to an understanding through the interpretation placed on a text through our own use of language as a process of questioning and answering (Gadamer, 2004). In the present of recalling in the interview above but now in the past, I was remembering a time many years before when as a nurse I had cared for women with advanced gynaecological cancer. But at the time of the Ben Lomond walk, it was only a vague feeling of uneasiness.

What then of a conspiracy of silence? If I had that awareness, an insight into a serious illness for my partner, why did I remain silent? Furthermore, when Jane observes "the days of bouncing up and back down again in three hours or so are long gone" why does she not question her poor fitness in an apparently otherwise healthy and health-conscious woman in her early fifties? I suggest that we were both mutually yet independently, engaged in a tacit conspiracy of silence. Zerubavel (2006) reviews the many forms and causes a conspiracy of silence may take and observes:

Silent bystanders act as enablers because watching others ignore something encourages one to deny its presence ... The discrepancy between others' apparent inability to notice it and one's own sensory experience creates a sense of ambiguity that further increases the likelihood that one would ultimately succumb to the social pressure and opt for denial. (Zerubavel, 2006: 55)

In the excerpt from my interview, I comment that "I didn't particularly notice that at the time" which seems to confirm Zerubavel's observation. There was a vague change in Jane's stamina, she had noticed her loss of fitness but neither of us voice any concerns. Pressed by the interviewer on

the point of either of us noticing anything to suggest a health issue for Jane, I recall a time some months earlier:

In Belgium, she said she felt as though she had this brick in her. Because we were displaced, we didn't have a GP [and] we had the language complication despite her fluency and the support that we would have had from the family we were staying with. I think she suspected there was something wrong but she didn't want to be ill in Belgium. She didn't want to be somewhere foreign and be ill. (Interview 1, 9 July 2013)

Despite these indeterminate concerns, we continue with the flat purchase; we also have consultancy work which takes us to London. We travel the day before, stay in our preferred hotel and dine in a favourite Indian restaurant. The following day we return by train; Jane has not been feeling well as I describe:

This particular evening we'd gone for an Indian meal and I remember being back in the hotel and her abdomen did seem to be distended and she was complaining of bellyache. We had some kind of homoeopathic digestive remedy which she was taking which was helping a bit. Then the following day when we were coming back, there's a moment, which I remember very, very clearly. When the train had pulled in to Glasgow Central and we're waiting for the doors to unlock, I looked at her and saw this huge distension of her abdomen and very consciously thought 'that looks like ascites but it can't possibly be, that's ridiculous'. I said something to her like 'gosh your belly's really swollen' and she just said 'yes' and she would be glad to get home. (Interview 1, 9 July 2013)

With the still clear memory of her lying in obvious pain and a very distended abdomen, it seems astonishing that neither of us sought help. It is perhaps understandable that Jane, who again found herself in a foreign land, as England was to her, wanted to wait until she was home but I had the experience, the knowledge that this could be something very serious. We were very near to a major London teaching hospital but there is no suggestion of doing anything other than trying our own various self-help remedies. There is a clear fusion between my awareness in the then present horizon when the thought arises 'that looks like ascites' and the past horizons of my nursing experience. My thoughts at the time even make use of technical terms that reference medical language. Yet I appear paralysed by our mutual tacit conspiracy that renders us blind to the situation. My memory of the ascites thought remained so clear it became the first day in what I term the Illness Period. My diary entry the following day is a curious mix of clinical observations, therapeutic intervention and witless humour "Jane not feeling that great today –

sore back and bellyache. Condition worsened this afternoon and evening – nausea etc, grey, abdomen very distended. Lunch and tea solo! (Personal diary, day 2).

The crisis comes during the night when Jane wakes me at 4.30am distressed and crying with the pain but we are not registered with a General Practitioner (GP). I call the NHS out of hours service and explain the situation and we are to make our way to a nearby treatment centre. Jane is seen promptly by a woman GP who thinks she may have an abdominal obstruction and refers her to the hospital conveniently across the road. I help her to dress and we walk across for her to get undressed again and lie on another hospital trolley. A tall woman comes, the surgical SHO (senior house officer), who examines her and arranges blood tests and x-rays. We wait for about two hours during which time the duty doctors changed shifts. The surgical SHO is now a young male doctor. He is cheery and upbeat: apparently constipation and a urinary tract infection (UTI). I am overwhelmed with relief and disbelief, while Jane is:

Just relieved that somebody had given her feeling of unwellness a label. The early hours of that morning she just felt so ill, and then she'd been poked and prodded and x-rayed and all the rest of it and eventually they had pronounced. I was beside myself with worry, I was absolutely convinced there was something very seriously wrong and I remember standing beside her on a trolley in a corridor and just this surge of relief and saying to her 'that's great, that's easily fixed' and her being relieved. (Interview 1, 9 July 2013)

Antibiotics and a bulking agent are prescribed and we drive home. For the next ten days we persevere with the treatment regime:

She looked very small and pale, with this big tummy, weak, and I had this kind of desperate feeling of wanting her to get better but alongside the antibiotic they'd given her this bulking agent. Not only did she feel completely blown up but she had to take this stuff that just seemed to to blow her up even more and then I kept looking for stuff on the internet about why did she have this abdominal swelling and I was getting answers like a swollen abdomen's ascites and you know why you get ascites. I kept pushing that away and we kept trying and following the treatment that had been prescribed. (Interview 1, 9 July 2013)

By now Jane's mobility is restricted by what appears to be a full pregnancy, most of her clothes no longer fit and she spends most nights pacing up and down in considerable discomfort. I register us both with a GP practice near our new home and she has an appointment on day 14, "Belly turns out is still constipation so bulking agent! Worked like devils removing old carpet in

the attic and Jane scrubbing in the bathroom” (Personal diary, day 12). The reassurance of the visit to the doctor seems to galvanise and energise us both. The flat needs a great deal of work including complete redecoration and a new kitchen but things are far from being right with Jane:

VA: I was just remembering that time, wanting desperately to fix her and knowing that it was way beyond anything I could fix or even that anybody else could fix. This wasn't good and beyond that I didn't think, I thought about the flat instead.

Interviewer: Okay, this is the difficult bit, there's a bit of a tremble and I just want to say that I'm noticing that.

VA: It was just this thing I think we both knew but didn't consciously acknowledge and certainly beyond saying that it would all be better when we got to Edinburgh, once we could, she just wanted to get into the flat. She just wanted to be in her own place, she wanted to be at home, in her home. (Interview 1, 9 July 2013)

It is the most bittersweet time; we both seem to know but we can neither acknowledge nor admit to ourselves or each other that she may be seriously ill:

She was in a state of tension and it was magnified by her own physical discomfort but also her her psychological discomfort of not being at home. So even though the flat was in a fairly ghastly mess, it was light, it was bright, it was airy, it stunk of cigarette smoke but that didn't matter, it was ours, it was a home and we were very quickly going to make it into a little nest that she would feel comfortable in. (Interview 1, 9 July 2013)

Given the poor state of Jane's health, this emphasis on 'being at home' may seem odd. Yet until she felt 'at home' she would not be able to let go and be ill. This was a liminal state, a transition between our previous journeying through Europe, to a home from home at Jane's maternal home, to the sense of permanence that one feels at home. I was unaware just how powerful a concept home was for Jane until I came to reflect upon it for this study. When we worked together in our home-based consultancy she had the habit at the end of the working day of announcing to the house that 'she was home from her work' when all she had done was walk from her study into the kitchen. While I can recognise that I like being at home, prefer to work from home and when away, like to get home, this was something more. Alsop (2002) although writing about studying away from home, discusses the difference between two German terms from which the English word *home* is derived. These are *heim*, simply home as we understand it in its various contexts, and *Heimat* which has a much more polarised sense of "the rather awful

prospect of living in a desert of the familiar, the same; at the other extreme it is a jewel, a gem, something special and very dear and precious to you” (Alsop, 2002: 2).

It was the latter that mattered for Jane. *Heimat* was also a German television mini-series of which we had watched all 32 episodes totalling 53 hours. Set in the Hunsruck it detailed life in west Germany from 1919 to 2000. When I asked Jane what ‘heimat’ meant, she explained that in a simple sense it means ‘homeland’ but in reality it is far more. The security of our sense of homeland allows an inner compass to develop. We are largely unaware of it until we leave resulting in a dialectic between home and away, between past and future (Alsop, 2002). When we are away from home we make sense of where we are by continually referencing it in terms of how it might be at home. Much of this may simply be a subconscious process of adapting to our new surroundings. Sometimes we may wish to escape Alsop’s ‘desert of the familiar’ in a rejection of Western culture and capitalism, as part of an existential becoming (Madison, 2006). Jane needed not just to be at home but also to lose the sense of homelessness from the months of travelling and to recover a sense of settled comfort. The idea of homelessness can be further extended to an interpretation of illness where one does not feel at home with one’s body. Drawing on Heidegger’s conception of *Unheimlichkeit* (uncanniness or unhomelikeness), Svenaeus proposes that this is the essence of illness when:

the mission of health care professionals must consequently be not only to cure diseases, but actually, through devoting attention to the being-in-the-world of the patient, also to open up possible paths back to homelikeness (Svenaeus, 2003: 14)

For Jane, unhomelikeness extended from not being physically at home, to feelings of not being at home in her body. We are about to discover that illness will compound her sense of unhomelikeness.

The preparations for our new home are a useful distraction but the conspiracy of silence continues and has widened to include other close family members, especially my sister. Perhaps most telling is Jane’s silence. She remains stoical and uncomplaining but by day 21, a week after the initial consultation with the new GP, she is in considerable pain. At night she paces up and down, unable to sleep or find relief from the pain and her giant, distended abdomen. We have a night in a nearby hotel in preparation for further flat arrangements. In the morning I make her an urgent appointment at the surgery:

The second time we went to the GP, it was the the same chap, the charming



young registrar but this time he had a female medical student with him. We had gone into the consulting room and I'd helped her up onto the couch and he'd prodded and looked at this belly and then said that that this was an interesting case and he'd like the medical student to examine her as well. What he was showing the medical student was that it was a very good example of profound abdominal ascites and you could do the wave test where you tap on one side and you can see the ripple effect across the abdomen. Jane was always in teaching mode or education mode or learning mode so if there was an opportunity to learn something, and she was a centre of attention in that way, then that made it okay, she could then intellectualise [it as] being interesting. So she could disassociate herself from this was her body that something clearly was going very wrong with. She could then almost be out of it and look at it as an interesting case and join in with the intellectual discussion. (Interview 1, 9 July 2013)

It is perhaps understandable that as Jane had previously been examined and x-rayed in hospital, that following the first GP visit, the diagnosis of constipation continued to be accepted as correct. I found it very difficult to understand this apparent body blindness to what seemed so obvious. The willingness to accept the initial diagnosis and not to see Jane's whole body disfiguration with her thin arms and huge abdomen was at best puzzling. Was this another conspiracy or just simple inexperience in a recently qualified community physician? A paradoxical explanation could be the notion of 'diagnostic creep'. The term was first used in relation to childhood problems of living when it was used to describe them as mental disorders (Anand & Malhi, 2011) and codified in the American Psychiatric Association's Diagnostic Statistical Manual (Farah, 2002). In the US, in particular, the term now has some variations:

Treatment creep is adding new medications without stopping the old.  
Diagnostic creep comes from multiple diagnoses with medications for each.  
Doctor creep involves patients securing drugs from multiple providers.  
Most iatrogenic is Pharma creep with a pill for every human unhappiness  
(Brendtro & Mitchell, 2013: 7)

Effects of this 'creep' can include a willingness to accept a diagnosis once it has been made or to overdiagnose; a result of wider definitions of disease and earlier detection (Moynihan et al, 2012). Doctors are trained to act, symbolised in general practice by the prescription which may be unlikely to make any real difference to the patient's condition yet there is "a pill for every ill" (Busfield, 2010: 934). For whatever reason, Jane's symptoms of bloating and abdominal discomfort could be accounted for by the earlier diagnosis of constipation. Malignant ascites, the accumulation of fluid in the abdomen as a result of neoplastic disease, only accounts for about

10% of all cases. Of those who do present with ascites, 50% do so at their initial diagnosis (Ayantunde & Parsons, 2007). In fact, abdominal bloating and its associated distension has become so common, one Canadian gastroenterologist has stated:

... most cases of functional abdominal bloating with visible abdominal distention can be explained by some combination of weak or inappropriately relaxed abdominal muscles, a diaphragm that contracts when it should relax; excessive intra-abdominal fat; fluid in loops of small intestine and gravity (Sullivan, 2012: 1)

However, something more serious is suggested at our second visit to the surgery:

The GP says that he's concerned this is clearly more than constipation and that he wants to refer her to the surgical receiving [unit]. So he writes the referral letter and we have to go there. [At the hospital] I help her get into a gown and up on the trolley and a young male doctor comes in and wants to examine her. I'm sitting on a chair but I stand up and say 'hang on a minute who are you and what is it you're doing'? He sort of jumps back and says 'oh he's sorry, he's doctor<sup>44</sup>'. So I said 'well that's fine' and I'm going to stay with her if that's okay with him and we agree that it is. He examines her abdomen and then does various internal examinations. Doctors learn very early on to have that kind of dead pan expression but I know that this is more and Jane knows but she is relying on me to protect her. So there's a lot of eye contact between us and and I'm making lots of reassuring noises. (Interview 1, 9 July 2013)

A 'posse' of doctors return with a plan: Jane needs an ultrasound and a referral to the gynaecologists who are based at another hospital on the other side of the city. The ultrasound cannot be done until the next day. There is then some prevarication about whether she should be admitted or allowed to go home. I negotiate going home, despite the 100 mile round trip. The inter-hospital referral letter summarises the situation:

Thank you for seeing this 50 year old lady so quickly in your clinic. She presented to us with a history of constipation and a distended abdomen gradually getting worse for the past 2 months. She gave a history of generalised mild abdominal tenderness as well, with no real distinguishing features. She also complained of the occasional feeling of lethargy. ... The impression is of a possible cervical lesion with an unknown cause for her ascites and we would appreciate your urgent opinion regarding this. (Hospital letter, day 21)

In the evening, I note in my diary:

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<sup>44</sup> This episode was prior to Dr Kate Granger's #hello my name is campaign (<http://hellomynameis.org.uk>).

Phoned GP this morning and went to see him. Clearly concerned and referred to surgeons. They thought they could feel something so referred to gynae. Can go back to Glasgow tonight but have to be back for scan at 9am. Worry makes the world go round. (Diary entry, day 21)

I remember the drive back to Glasgow as a quiet run, neither of us saying much. We did console ourselves with the prospect of being in our new home, reassuring chat that all would be fine once we were in the flat, just us and the two cats. Whatever is wrong with Jane, we are certain that as she is otherwise fit and healthy, we will be equal to any challenges.

### 4.3 *Finding*

In this episode the cause of Jane's symptoms is discovered following an emergency hospital admission and a provisional diagnosis of advanced ovarian cancer is made. It begins with an unsettled night for us both then the drive back to Edinburgh where we report to reception at the specialist centre for reproductive health. My memories remain vivid:

We were told to wait in an area for ultrasound but what was very strange and I think what was very difficult for her, was that the unit in the hospital is both for women with gynaecological disorders but also for women who are pregnant. So most of the ultrasounds and certainly all of the other women that were waiting were obviously pregnant and Jane looked both older and whilst at first glance she might have looked pregnant, she also didn't look right. The radiographer was on one side and I sat on the other and they started doing the ultrasound. Quite quickly the radiographer could see there was a mass and she started measuring it and called to her colleague. They were talking about 12cms. I was making reassuring noises but we were just kind of exchanging looks that said yes there is something. (Interview 2, 13 August 2013)

Following the ultrasound we are ushered by a senior nurse to a side room with a hospital bed. Later I learnt this is a triage area for gynaecological emergencies. A woman in theatre scrubs comes to explain the surgeon is in theatre but he will come as soon as he was free. Something has changed, I can see it in the nurse's face, nothing is too much trouble, the situation has shifted, this is really serious:

VA: Eventually [the surgeon] came and was very smiley and charming and asked Jane all sorts of questions about her medical history and how long this had been going on for. Then he wanted to do an internal examination but she was in an extremely uncomfortable position and when he tried to examine her, it was excruciatingly painful. He didn't really try very hard and just sort of said no, it was okay he would he would leave it. What he really

needed to do was to take her to theatre and do a diagnostic laparoscopy to see what was going on. He could get her into the end of the list that day and so that was the plan but she needed to go and have a chest x-ray. Then we were sitting waiting and suddenly the surgeon reappeared and said right, that was it, he was ready for her and he whisked her off upstairs. There wasn't anything else I could do, there was no point in me waiting I just had had to leave.

Interviewer: How was she when she heard she was going to have to go to theatre that day?

VA: Oh, she was excited, she'd seemed quite small a lot of the time. If I say she was almost child-like, I don't mean that in a derogatory sense but there was this kind of wide-eyed innocence and part of that wide-eyed innocence was curiosity to what was going on, what was happening. She hadn't ever spent a night in hospital all her life. I think it was almost part of her coping mechanism to ignore the fact that it was her body that was being looked at and poked and prodded and examined. This was something exciting that was happening. Her father had been a laboratory technician and so she had that sort of medical curiosity of what's going on. Wanting to know and I suppose consoling herself with what her dad would have thought of it and how she would tell him all about it. (Interview 2, 13 August 2013)

I remember walking away from the hospital to spend the first night in the flat alone and phoning her mother to explain something had been found and that a small, exploratory operation was needed. We both had difficulty speaking, neither one wanting to acknowledge what we both feared. Any conspiracy of silence had gone, replaced by a state of fearfulness. Denial of serious illness is a complex concept that originated in psychotherapeutic practice with patients who had difficulty in accepting what had happened to their bodies. It can range on a continuum through non-acceptance of diagnosis, minimising the seriousness of their condition, delay in seeking help, poor compliance with treatment and appearing to have an unperturbed detachment with regard to their illness (Goldbeck, 1997). It may be perceived by health professionals as either an ineffective defence mechanism or as an adaptive strategy for coping with overwhelming feelings and events (Vos & Haes, 2006). For Jane, and indeed for me and her mother, there had been a denial of illness but privately we all had our suspicions. It was only when the bodily illness could no longer be concealed that its presence was accepted. A diagnosis of cancer is anticipated by all three of us; denial had been a temporary adaptive strategy.

It is three weeks before Jane writes a blog post about what has happened. Then she tells the whole story starting with the journey back from London, the constipation diagnosis and the

laparoscopy to the first chemotherapy session. Consequently, in order to include her version of events, the chronology is slightly distorted as is the tenor of her voice. She is upbeat, humorous, her usual witty self but by the time of writing, she knew the extent of the disease and the treatment plan. She sets the scene at the outset, acknowledging the delay and her intended purpose in writing the blog:

Our little world turned upside down and it's taken a wee while before I've felt able to write about what's been happening. In short: I've been diagnosed with ovarian cancer. Now I really do not want the account of our lives and journeys I've been keeping here to turn into 'yet another cancer blog'. What follows is rather long, and quite personal, perhaps too personal, and with too much information for some. But there's nothing like having cancer to illuminate starkly what really matters in life, removing prevarication, inhibition and equivocation. It gives focus, makes you honest, strips you bare. (Blog post 'Silver linings', day 44)

The authenticity of her account following this blunt introduction is accurate, almost as if she had a video recording of the proceedings. This may be accounted for by the heightened awareness experienced in times of anxiety through the fight or flight response (Cannon, 1932). Barbara Rosenblum described how her training as a sociologist made her acutely aware of the demeanour of her doctor during their first clinical encounter, "I searched for clues to anticipate what she would tell me" (Butler & Rosenblum, 1991: 10). I had recognised something similar in the way Jane comported herself in hospital as I recall in the interview excerpt above "that wide-eyed innocence was curiosity to what was going on, what was happening" (Interview 2, 13 August 2013). That wide-eyed curiosity is apparent in her description of the ultrasound and other investigative procedures:

The following morning I reported there for an ultrasound and it was pretty clear from the picture, and the whispered conversations ('I can't find the left ovary', 'Just take measurements then') that there was indeed something unpleasant in my pelvic area. The gynae consultant came down, tried to do an internal, pronounced himself 'confused' by what he'd found, and admitted me for exploratory surgery. I had an examination under anaesthetic and a diagnostic laparoscopy later that afternoon (the consultant having gone to some lengths to make space in the schedule, and to persuade the anaesthetist to admit me to theatre without his usual checks – 'My colleague assures me you are strong and fit and a suitable candidate for surgery, so I'm just going to knock you out now.')

Then I got to spend my first ever night in hospital, and the following morning had an MRI scan and CT scan. Both fascinating procedures: the

CT scan a huge spinning wheel of lasers issuing breathing instructions in a vaguely amusing mid-Atlantic accent; the MRI scan that big scary washing machine thing that swallows you whole served up on a metal tray. I overcame any sense of claustrophobia by pretending to be Sigourney Weaver settling down for the trip back to Earth at the end of *Alien* (not entirely inappropriate given the enemy currently consuming me from within). I accepted the offer of classical music for the 25 minutes the scan was to last. Should have had money on the playlist: Pachelbel's Canon, Albinoni's Adagio, Barber's Adagio for Strings, Rachmaninov's 1st Piano Concerto ... all good relaxing stuff if you like funereal music. (Blog post 'Silver linings', day 44)

The trope most apparent to me in this extract is the use of irony although it will be less obvious to a reader who had not known Jane. Initially, by quoting the overheard comments, she gives an ironic slant to the proceedings, as if the health care professionals appear befuddled by her curious case. She then shifts to using wistful metaphor in her recollection of Sigourney Weaver as the heroic Amazon who has slain the demonic alien. In her mind's eye she recalls the image of a slim, lithe and calm woman (her ideal type) resting quietly in her sleeping pod on her voyage back to Earth. In a review of the *Alien* trilogy, Murphy makes some interesting observations pertinent to this study, the first being on the concept of home:

In the nothingness of outer space, the integrity and particularity of flesh is everything. Home is literally where the heart is – the body being the last bastion of warm, colourful, imperfect, familiar biology in a totally deracinating environment. (Murphy, 1992: 17)

Here the irony becomes apparent, as Jane finds solace in her own warm body it is also in full awareness of the alien presence within. For now she can take refuge but in her disembodied state she hears 'funereal music', a portent of what lies ahead, beyond this liminal place. But her focus will have been on the memory of her heroine, she is yet beautiful:

And the celebratory inventory of the elegant lines of Ripley's torso and her long, bare arms and legs mark precisely *Alien's* mortal stakes. These fleshly signatures underscore the strength and beauty of the human body, differentiating it from the alien anatomy (Murphy, 1992: 18)

The real irony is if Jane had been asked to name four pieces of classical music she most disliked, she would have named the four played in the scanner. The calming and well-intentioned music will have been a grating irritation and anything but relaxing. Lambeck (2003) has suggested that there are two forms of irony pertinent to illness: irony of commission or intentional and irony of recognition or found. It is reasonable to assume that there was no deliberate intention on the

part of the technician to play what some might perceive as funereal music. However, it could be classed as an example of irony of recognition: Jane not only recognises the music being played but also its associations in other contexts. Lambeck (2003: 1) suggests that “therapeutic practices and discourses can be described and distinguished according to the degree to which they recognise or refuse irony”. In this regard I believe it was simply an innocent lack of awareness of music as a powerful synaesthetic agent (Campen, 2014).

Later, when we talk about the episode and by way of preparation for the many scans she will have, I ask if she is going to mention the music and propose something from her own playlist. She thinks not; she would not want to make a fuss or draw attention to herself. This reticence was unusual as previously if something was not to her liking she would have said as much but now it seems it is either less important or the effort is too much. She can make a fuss within the privacy of her own home but does not want to be exposed in the public, clinical space. A more likely explanation is that of feeling powerless at the enormity of her diagnosis (Sand et al, 2007). If we are to believe the veracity of the blog post, *Silver Linings*, the diagnosis was a shock but Jane does not appear powerless. One interpretation of powerlessness is to view it as something from which empowerment, with features of self-awareness and self-determination, can evolve (Aujoulat et al, 2007). Furthermore “the notion of empowerment should therefore extend to decisions such as the decision to hand over one’s responsibility for disease and treatment, provided the decision is sufficiently informed and self-determined” (Aujoulat et al, 2007: 772).

This seems a more plausible explanation; there is little Jane can *do*, she just has to endure procedures, treatment or even ubiquitous music. It is human nature to assume an active role in response to any given situation but this may not always be possible or appropriate. Jane understood this through her understanding of Goethe’s synthesis of thinking and doing (Plenderleith, 1993). She is content to swap *doing* for *being*, passively thinking and absorbing all that happens around and to her. This dialectic process is a process of becoming (Wilcock, 1999), a transition from who she thought herself to be, to who she is now becoming.

The next day I want to go to the hospital as soon as possible but Jane calls to say she is fine; I should wait until lunchtime when the doctor will explain what has been found. In the second interview, I am asked what Jane might prepare herself for:

I don’t know at what point she must have realised. Actually I think she knew when they did the ultrasound because we both knew that there was a large tumour and so then what she was preparing herself for was how they

were going to get rid of this thing and make her better. She was quite upbeat, they had found something and they'd taken the biopsies. The next step was to be seen by the oncologist and then if they were able to shrink the tumour, the surgeon would then be able to remove it. So, although the news was devastating, there was a positive plan. (Interview 2, 13 August 2013)

There are further tests to be done before she can leave but finally we are given a discharge letter for the GP and a supply of a cloyingly sweet high protein drink. This is to counter the loss of albumin when the ascites was drained in theatre. I read the discharge letter and see words that burn my eyes "peritoneum obliterated by disease, widespread miliary disease in pelvis, pelvic organs stuck, tumour in omentum. Not surgically resectable. Diaphragms covered, porta involved" (Hospital discharge letter, day 22).

A distant horizon brings the word *carcinomatosis* and the thirty year old memory of a woman, a teacher in her early fifties, with luminous, foul-smelling liquid oozing from her bloated abdomen. I was a student nurse, horrified by the sight, the stench and her suffering. The famous line from Wilfred Owen's (1920) *Dulce et Decorum Est*, "Gas! Gas! Quick, boys! – An ecstasy of fumbling" is apposite as I recall the bedside scene. It was the second year of my nurse training but still I fumbled in embarrassment for fear of showing my revulsion. Then the woman in her sixties, when I was a third year on night duty, with the fistula between her vagina and rectum constantly leaking foul-smelling liquid. I did not speak of these horrors; Jane cannot understand why I am so upset. She is content with the plan as presented. I am thankful she does not realise that miliary disease means the primary tumour had already 'bloomed' and secondary, metastatic disease has spread within her abdomen. I now realise that if the disease had not been found then, she would probably have died within a few weeks. The ultrasound report confirms the off-stage whispers we had heard during the procedure:

Technically difficult ultrasound examination. The uterus and left ovary was not visualised. There is a solid and cystic mass extending from the right side of the pelvis to the left, this is highly suspicious of a right sided ovarian malignancy. The mass measures approximately 92x56x75mm. Significant free fluid noted in the pelvis and abdomen. (Ultrasound report, day 22)

I note in my diary "the doctor came and confirmed our worst fears ... bit shell shocked" (Personal diary, day 23). Terror management theory (TMT) is a useful way for clinicians to interpret their anxieties when they feel a patient may be in denial of serious illness (Rayson, 2013). TMT was first proposed in the 1980s (Greenberg, Solomon & Pyszczynski, 1986) and



based on Ernest Becker's idea that most human action is taken to avoid or ignore death. TMT is centred on self-esteem as an essential mechanism that acts as a buffer against existential anxiety. The terror of our own death is ameliorated by how good we feel about ourselves. The sense of personal value extends to a sense of how we might 'live on' after physical death in either a literal or symbolic sense. Belief in an afterlife or heaven provides literal relief of death anxiety while having children or particular life achievements affords symbolic relief (Burke et al, 2010). Rayson summarises TMT in the context of palliation as "Our patients know the end is coming. We know the end is coming. We all need to keep on keeping on" (Rayson, 2013: 4372).

Now we both know the end is coming, yet Jane's horizon is two years. She believes and has complete faith in the proposed treatment plan. This is consistent with the finding that cancer patients are much more interested and focused on treatment than on prognosis (Salander, 2002). It is also consistent with the earlier insight from TMT where Jane's courage and energy can be deployed in feeling good, despite the news, there is treatment available and she will try her best. However, the news of her illness now needs to be broadcast to our immediate family:

Interviewer: So that night, she phoned and told her sisters. How did she prepare herself to do that?

VA: Well, we'd driven back and told her mother. I think in telling her mother, as a linguist Jane was very good at rehearsing what she wanted to say and so it didn't really matter whether she was going say it in French or German or in English, she would rehearse. She would have rehearsed in her head what she was going to say and the way in which the news would be presented. So yes, there was bad news but there was a positive message that the surgeon had taken biopsies and the oncologist would then know what kind of chemotherapy to use. The tumour would shrink and the surgeon would then remove it. So it was very much presented as a complete package without any kind of question that maybe the tumour wouldn't respond or the surgeon might not be able to remove it. (Interview 2, 13 August 2013)

As with Schaepe's (2011) finding that the diagnosis maybe conveyed incrementally by different clinicians until the ultimate meeting with the oncologist, so it is for Jane. At this point the information is equivocal, nothing would or could be confirmed until the pathology report is received and the oncologist is able to determine the precise type of chemotherapy to use. Questions regarding prognosis do not arise; it is enough to try and understand the provisional diagnosis. However, in a systematic review of conveying cancer prognosis, Hagerty et al (2005) recognised the desire of patients to be more involved in the decision making process regarding

their care and treatment.<sup>45</sup> But the emphasis is on the best method of communicating prognosis based on patient preferences. The enormity of that first 24 hours is evident in my diary entry the following day:

So many tears shed in the last 24hrs but J incredibly brave and stoical. She told [her sisters] last night and I phoned [my sister]. Today we just tried to get our heads around the basics and will now get decorators to do flat.  
(Personal diary, day 24)

In the interview excerpt I say “as a linguist Jane was very good at rehearsing what she wanted to say” which encapsulates the essence of the unfolding drama in which we now find ourselves. The first definition of a linguist is a person skilled in languages, and the second is someone who speaks freely and eloquently (SOED, 2007). Jane had both of these attributes. Part of her rehearsal process is not just to work out in her mind the correct words and grammar to use but also to tell it in a pleasing way. So there is bad news, cancer, but this is quickly assuaged with good news, treatment plan, all packaged in a few succinct and eloquent sentences. Of course her mother already knows when she is told, as mothers do, for she has noticed Jane’s ‘scrawny neck’. I am not surprised she realised there was something seriously wrong with her daughter nor that she joined in the conspiracy of silence. The dissemination of the news becomes easier for Jane as she works her way down through the layers of family, friends and work colleagues she wants to tell. Stacey considers the effect on relationships as she describes the process for each outsider as they gain this insider knowledge:

A complex interchange of projection and protection is at play in this process of sharing the news. Has so-and-so heard? How did they react? And through their shocked reaction your own sense of discrepancy between who-you-thought-you-were and who-you-must-now-be is repeatedly rehearsed. (Stacey, 1997 :70)

The dance has started and the first few steps set the scene for how the entire dance will play out. The process for selecting the corps de ballet to support the two principals is underway. The company quickly self-selects itself as those family members and friends, who for whatever reason do not want to join the dance, slip away. Curiously as the news spreads, long lost friends reappear and join the dance, staying to the end. The reactions of others to the news is not lost on Jane either:

Other people react to my cancer in interesting ways. Some stay away, not, I

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<sup>45</sup> This point connects with Section 2.2.2 regarding value-based medicine.

think, in case they catch something nasty, but simply because they don't know what to say. Mostly people rally round. We take huge comfort from the overwhelming waves of love and support and concern, popping in to say hello, the phone calls, emails and texts that just stay in touch and say 'we care', the offers to help in any way possible. I'm figuring in the prayers of a lot of people including the Iona prayer group (special because Iona is special to us, where serenity meets energy). I'll take all the help I can get. Francophones send courage. [A cousin's daughter] wrote 'Dad and I were just saying if anyone can beat this, Jane can'. That sort of ringing endorsement does a power of good. (Blog post 'Silver linings', day 44)

My own role is already heroic, Amazon carer:

What I didn't want because I knew, my imagination was running away with all the things that she was going have to face, but I didn't want her to be fearful. I wanted her to feel safe and as protected as possible, that she wasn't alone and we'd make it as easy as we could. She wasn't to fear that she would be in pain or that it would be too horrid or whatever, that it would be okay. That was right from the diagnosis, that was hugely important, that I was there and with her all the way. (Interview 2, 13 August 2013)

In the telling of the news she is perhaps doing as Butler and Rosenblum (1991) suggest and not just communicating her difficult situation but also recruiting supporters to her cause. This is in part confirmed by an email from my sister "it felt good to feel the circle of love and connection between us all ... the pair of you mean the world to us". (Personal email day 28)

We waste no time in the week between the diagnostic laparoscopy and the first appointment with the oncologist, getting Jane into training for the challenge ahead. She rests with her very oedematous legs elevated, drinks the saccharine protein drinks and generally takes life easy. I rush about like a woman possessed, which of course I am, continually haunted by dark thoughts, and fuss over Jane to her mild irritation. The culmination of my experience as a nurse with some insight into gynaecological cancers and expertise in the care of the dying have the makings of a *return enhanced*. Lay carers may have feelings of uncertainty and a lack of rehearsal when preparing to care for a partner or relative with advanced illness (Newbury, 2009). A sense of disruption and unpreparedness is evident in the artist Marion Coutts' first hand account of caring for her husband with glioma (Coutts, 2013). As I prepare to care for Jane, I do not have these feelings nor have I lost my sense of self by becoming bound to Jane's dependent body (Jenkinson, 2004). I care for Jane's body but it is not the body I know in intimate detail, for that

seems to have gone forever after her sojourn in hospital; replaced by a bloated and disfigured shape as a semblance of her former self.

We return to Edinburgh for the first night in the flat sans furniture apart from a studio couch. I make an impromptu recliner for Jane with a camping chair and a discarded stool. We sit in the window looking at the view of the Pentland Hills and the clouds, on the edge of excitement. The meeting with the oncologist is the following morning when the great plan will be revealed.

#### **4.4 Planning**

In the last story in this chapter, we attend the first clinic appointment with the oncologist, learn the outcome of the pathology report and the forward plan for Jane's care. There are three different accounts of the meeting, first my interview recollection is intended to set the ethnographic scene. Then the oncologist's medical case note provides confirmation and finally Jane's blog post is the dance director's version for public broadcast. The appointment is at the same hospital Jane attended when referred by her GP. It is also where I was a ward sister and a night charge nurse in the then radiotherapy unit and now the regional cancer centre:

The clinic itself was a relatively small area but what I really remember was that there were a lot of women there already, maybe six or so and they all had somebody with them. They all looked just pained and anxious and some were quite tearful. There was an absolutely palpable tension; we were told to sit down and wait. I'd taken the iPad because as long as Jane had something to distract her, she could just hold that and lose herself in something and not be drawn in to this tension.

Eventually it was her turn to be seen and this youngish chap came and we were ushered into a consulting room. We sat down and we'd rehearsed some of what we might say. We understood that this wasn't good news, it was quite serious. So he explained that the pathology results were that it was a serous cell tumour and the staging was 3c which is not quite the worse; the plan would be to start chemotherapy. Then he said he would try and see if he could get her into the chemotherapy unit to start treatment the following day.

We went back out into the waiting area and it felt like this huge relief because treatment was going to start as soon as possible and that meant a huge amount to Jane. Although this had taken a long time to find out, as soon as they knew they were going to react as quickly as they could. So although there was still this tension, these unhappy women sitting there, she was almost smiling because she was going to be fixed. Then he came back and said yes indeed, he'd managed to get her in, they would do some

bloods and there were pills that needed to be taken the night before. So that was it and off we went, almost excited. (Interview 3, 20 August 2013)

Once again a performance has been rehearsed and given in a private audience. I am carried along by Jane's enthusiasm for quick action, her complete faith in the Scottish NHS and some private pride that *my* hospital is preparing to give her the best treatment available. The oncologist summarises his findings in a letter sent to the GP:

The lady has a Grade 3 Stage 3C serous papillary ovarian carcinoma. It is clear that this has progressed rapidly and the extent of the disease is considerable. We had a discussion about the aims and side effect of Carboplatin and Paclitaxel chemotherapy. The lady and her partner were already well up to speed with the situation and the precarious situation that she is in. I felt that in view of the rapid progression of the disease that we had to initiate chemotherapy straight away and therefore I have arranged for the lady to receive her first cycle of chemotherapy tomorrow. She will receive 3 cycles of 3 weekly chemotherapy and then immediately after this will have a CT scan so we can consider whether interval debulking is a possibility. The lady knows from her consultation today that this is very far from certain as the extent of her disease makes surgery a very big undertaking indeed. (Hospital case records cover sheet, day 30)

The oncologist's account confirms we gave a reasonable performance and conveys our genuine understanding of Jane's situation. He really wants to help, to see if there is the slimmest chance that the tumour will shrink and that surgery will be possible. It is clear from the following extract she has heard and understood a great deal of what was said and the reality of her situation:

It's a bit of a facer when your world turns upside down and everything you've planned for, everything you thought was important, suddenly and seismically shifts. The full diagnosis was revealed by my lovely young oncologist (yes there is a pattern here, I am surrounded by lovely young highly intelligent capable professionals) the following week. Here it is.

I have a Stage 3 serous tumour which started on my left ovary (or fallopian tube, there's some debate), has munched its way through most of my uterus and 'involves' (they're not sure of the extent) the bladder wall and the rectum. It has also pressed on the ureter to the extent that my left kidney has stopped functioning. Treatment is to be four cycles of chemotherapy in the first instance, which they hope will shrink the tumour to an operable size, then a hysterectomy. He said that [the surgeon] has told him they are going to have to do 'a really good job with the chemo' and that is exactly what they are trying to do. I'm not sure how he did it, he had to move a few

mountains or sell his soul or both, but he persuaded the cancer day unit to admit me for my first chemo session the following day. Officially, then, from diagnosis to chemotherapy in less than 24 hours – I will never again hear a bad word about our NHS.

Our meeting with [the oncologist] was really interesting. He started with his concerned ‘I’m sorry to tell you you’ve got cancer’ face and tone of voice, closely followed by what is apparently the next worst thing he can tell you, ‘now you will lose your hair ... but we can give you a wig!’. But when we reassured him that this news was not entirely unexpected, that we’d had a pretty good idea of the size and shape of things to come when we’d left the hospital the week before, had got our heads round things, and no thank you I did not want a wig, his whole tone and demeanour changed. He went through my family health history in some detail, suggesting that there may be a genetic trigger for ovarian cancer in one so young as me (hah!). We wanted him to know that we’re in this together, that I have huge support at home (practical, clinical and emotional), that we are really positive about the treatment, will do all we can to maximise its effectiveness, and have every confidence in the team that’s looking after me at Edinburgh, that we have an intellectual as well as personal interest in what’s going on, a lifelong concern with education and research, and that I am more than happy to be a teaching case or participate in medical trials. (Blog post ‘Silver linings’, day 44)

Following the diagnosis and meeting with the oncologist, neither of us is inclined to search for information on the internet or read booklets from support agencies such as Macmillan. I download the SIGN (Scottish Intercollegiate Guidelines Network) Guidelines for the Management of Epithelial Ovarian Cancer (2003) but do not discuss the details with Jane. I just want to refresh my understanding of the disease and to confirm she will be getting the best treatment available. These summary points seem relevant to my understanding of Jane’s situation (SIGN, 2003: 1):

- Ovarian cancer is the fourth most frequently diagnosed cancer in women in Scotland, representing 4.6% of all newly diagnosed cancers, or around 600 new cases per year in Scotland
- The aetiology of the disease is unknown and is more common in women who have never been pregnant
- Among women in Scotland with no family history, the lifetime risk of developing ovarian cancer is estimated to be 1 in 59

- Survival is dependent on the stage of cancer at initial presentation – whilst stage I disease has a five year survival rate of 85%, stage IV disease has a five year survival rate of only approximately 10%
- Epithelial ovarian cancer is described as a silent killer as in over 60% of cases advanced disease is found at initial presentation

The goal for health professionals must be to ensure that where cure is not possible a woman can have a good quality of life with judicious use of surgery and chemotherapy

My clinical curiosity is overwhelmed by the stark confirmation of the evidence; the outlook for Jane is not good. Most of the terms I hear being discussed or read in the discharge letter, I know and understand apart from ‘neoadjuvant chemotherapy’. It came into medical parlance in the 1990’s to indicate the use of systemic treatment, either chemical or radiation, prior to local surgical intervention particularly in cases of solid tumours (Trimble et al, 1993). Its use in our context is entirely consistent but some have proposed:

Terminology in medicine should be lucid, understandable, consistent and unambiguous. The technical meaning of each term should correspond closely to what is generally understood by ordinary people, thus excluding confusion between patients, clinicians and researchers. (Habbema et al, 2004: 1499)

This may seem a little strong given that we do understand most of what is said and the health care professionals are also aware of my nursing background. Nevertheless there is a continuing tendency to use highly specialised medical language with the assumption that its understanding is unnecessary for the general public despite the increasing use of the internet as patients try to understand their medical conditions and treatment regimes. Awareness of new treatments and active research trials is openly encouraged by charities such as Cancer Research UK who provide a comprehensive website with easy access to information regarding current trials. It is claimed by Cancer Research UK that more people in the UK participate in trials than anywhere else in the world. The guidelines on epithelial ovarian cancer were updated in 2013 and the revised version makes some additional points regarding the detection of ovarian cancer in primary care (SIGN, 2013):

- Retrospective studies show that women with ovarian cancer present with non-specific symptoms including abdominal pain and bloating, changes in bowel habit, urinary and/or pelvic symptoms
- Cachexia (weakness and wasting due to serious illness) is uncommon and women with advanced disease often look surprisingly well
- On average, a GP will see only one new case every five years (Hamilton, 2012)
- Patients who present with non-specific gastrointestinal symptoms may be misdiagnosed as suffering from irritable bowel syndrome

Ovarian cancer therefore is a relatively rare disease that can present with a variety of vague and confusing symptoms which may have never been seen by the primary care physician. However, in the intervening ten years between publication of the two guidelines there has been a rapid increase in both research into ovarian cancer in general and awareness raising of the most common symptoms. The ovarian cancer charity, Ovacome, launched a campaign in 2010 using the acronym BEAT:<sup>46</sup>

- B for bloating that is persistent and doesn't come and go
- E for eating less and feeling fuller
- A for abdominal pain
- T for telling your GP

In 2011, the National Institute for Health and Clinical Excellence (NICE) published guidelines on the initial recognition of ovarian cancer by clinicians. It recommended that tests should be carried out in primary care on women, especially those over 50, who have any of the following symptoms frequently or persistently, with particular attention to more than 12 occurrences in a month:

- persistent abdominal distension ('bloating')
- feeling full (early satiety) and/or loss of appetite
- pelvic or abdominal pain

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<sup>46</sup> <http://www.ovacome.org.uk/beat-ovarian-cancer-with-ovacome.aspx>



- increased urinary urgency and/or frequency (NICE, 2011: 10)

Jane had all of these symptoms and was seen by four different doctors (two men, two women), all in the first few years of their careers, none of whom seemed to recognise a pattern. NICE is an agency that operates in England and Wales but there was also similar information in the first Scottish guideline (SIGN, 2003). It is a commonly held belief that delays in the diagnosis and treatment of cancer have a negative impact on survival yet delays are approximately equal in attribution to both the patient and the GP. Furthermore these delays do not affect survival of ovarian cancer beyond 18 months (Kirwan et al, 2002). The experience of an average general practice in seeing more unusual conditions was described in the 1960s as an illness iceberg, disease which is known to the average clinician but is undetected (Last, 1963). Hannay (1980) developed this idea by contrasting the iceberg of illness with trivial consultations that were bothersome to GPs. He concluded that there were significant symptoms in the community that were not reported to family doctors especially by middle-aged women. The term ‘illness behaviour’ (Mechanic, 1962) was first used to account for the different ways in which symptoms are perceived and acted upon, including being ignored, by individuals.

The delay in seeking help when faced with some bodily change could also be understood from inner and outer body perspectives. Inwardly there may be recognition of some vague symptom or change in bodily function but to acknowledge it is potentially to take it out into the world, perhaps even to health care. If the change has not been recognised or sanctioned by a family member then it can be even more easily dismissed as something trivial (Smith et al, 2005). Making the shift to understand the true meaning of a bodily disturbance may be a “breakdown in accommodation” (Radley, 2004: 73) and is based on Zola’s five ‘triggers’ to seek medical attention, “an interpersonal crisis, *perceived* interference in relationships, sanctioning when someone else takes the decision, *perceived* interference with physical activity and recurrence or existence of signs over a period of time” (Zola, 1973: 683, original emphasis). In the blog post when she announces her diagnosis, Jane reflects on her awareness of the illness:

I arrived back in Glasgow on a train from London after a meeting one evening in the middle of June with an aching back (I’d had a sore back for months, which we put down to strange spare beds and the left-hand drive car) and a swollen, painful abdomen. After a couple of sleepless nights we decided something had to be done. (Blog post ‘Silver linings’, day 44)

Here the breakdown of accommodation is the persistence of a symptom over time, 'a sore back for months', and the interference of physical activity, 'after a couple of sleepless nights' that results in action, 'something had to be done'. There is also the suggestion of sanctioning by the use of the plural 'we decided', she had my agreement that help should be sought. Earlier I have suggested there was a conspiracy of silence when Jane appeared to be unwell yet colluded in an unspoken tacit agreement to ignore her situation. I am also aware of an element of bystander apathy, a state of personal indecision and conflict concerning whether to act or not (Latané & Darley, 1969). However, I know that any vacillation on my part did not affect the outcome (Kirwan et al, 2002). There is also little to suggest that investigation any months earlier would have made a difference. In a study of more than 800 ovarian cancer patients "Use of symptoms to trigger medical evaluation for ovarian cancer is likely to result in diagnosis of the disease in only one of 100 women" (Rossing et al, 2009: 222).

My reaction to Jane's cancer is completely foregrounded by my past experience: it is impossible for me to think of her situation without recalling the women I had cared for in the past. My comfort zone is to try and engage with the clinical aspects of the diagnosis and the treatment; I want to be included in the discussions of the health care team. My dialogic self (Hermans, 2001) needs conversations about what is happening and I cannot discuss clinical details with Jane. I can supply any amount of discrete detail and support but not the dark history of my experience. Nor can I begin to imagine how it is for Jane, what she really feels. I deflect direct questions with simple enquires as to how she is doing and that is understood to encompass a myriad of possibilities. Then she gives the public a version of her feelings:

My reaction to cancer is quite interesting to me too. It's another adventure. Not one we would have chosen to undertake, but it has presented itself and has to be undergone, and overcome, with as much grace and dignity as it's possible to muster. It's also quite an education (a recent article in the Guardian expressed the educational aspects of cancer far more elegantly than I can). I don't feel resentment, or fear. I'm not asking the two unanswerable questions, 'why me?' and 'how long have I got?'. I didn't think I was angry but I have been responding with disproportionate fury to slight irritations, so there may be something to work through there ... There's nothing like cancer to restore perspective on what really matters in life. (Blog post 'Silver linings', day 44)

First she first uses her usual upbeat style turning the experience into one that can be understood through education. The article to which she refers is a personal account of living with multiple myeloma, by the late American author Mike Marqusee. I believe this is what appealed to her:

But what exactly have I learned? To begin with, that any glib answer to the question misses the core of the experience – the complex dialectic of being ill, which is a social as well as physical condition. For me the experience has led to a heightened awareness of both our intricate dependence on others and our deep-seated need for independence. (Marqusee, 2011: 1)

She was, as I recall, acutely aware of her dependence on others, not just on me but all of the people involved in her care, her team of health care workers as well as friends and family. What made her angry was not so much the disease itself but the impact on her fiercely held independence. She deeply resented not being able to gallivant about as she had done, as she was so very used to doing.

The three accounts of Jane's treatment plan that have concluded the final story in this chapter, typify the two most common approaches to medical interpretations of health and illness. These are the naturalistic approach, the familiar territory of clinicians which objectifies biological dysfunction, and the normative approach of the social sciences that evaluates illness in social terms (Carel, 2008). Yet neither of these positions satisfactorily accommodate the sufferer's perspective on what it is to be ill. The philosopher Havi Carel on discovering she had a life-limiting lung condition, decided to investigate the phenomenology of illness. She argues that it is living in the present that can most overcome the suffering of past memories and future fears, and concludes "Sometimes my illness makes life hard. It often takes up more time and space than I would like it to. But it has also given me an ability to be truly happy in the present, in being here and now" (Carel, 2008: 135).

## 4.5 *Summary*

In the next chapter, I will present evidence which I believe fully endorses Carel's thesis with regard to Jane's experience of life-limiting illness. This chapter has presented the first three stories in the Dance to Death: Wondering, Finding, and Planning. Data from all three substantive sources: Jane's blog, my interview recollections, and the health records were used to detail the first few weeks of the Illness Period.

## 5 Days for Dancing

### 5.1 *Introduction*

This chapter covers the longest period in the overall account, a total of 147 days and spans six months. It begins with the pivotal point from the previous chapter when the diagnosis has been confirmed and plans for treatment with chemotherapy have been agreed. Again there are three stories: Treating, Turning and Living. As before, these titles reflect the defining theme during each phase.

### 5.2 *Treating*

Following the first clinic consultation, we again camp overnight in the flat before returning to the hospital for the first treatment session. I had no real experience of chemotherapy but understood the basic process. We are both wide-eyed with ignorance and expectation:

VA: It started at five o'clock in the morning when she had to take a large amount of dexamethasone and have a banana. We hadn't realised that she would then bounce around for the rest of the night. So I didn't get much sleep and she was as high as a kite. The actual starting process was quite involved. There was a lot to explain about the treatment, what alternative therapies and vitamins she could take, what might interfere with the actual treatment. This process of things being explained and lots of leaflets took at least an hour.

VA: The actual treatment cycle is quite long as there's a number of different drugs. The other thing that you become so aware of is that because everybody has one or more infusion pumps, they're constantly beeping. Some of the infusions are only about 15 minutes and then they beep, beep, beep so there's this constant melody. Except it's not really a melody at all, just a cacophony of beeps. We'd been there all day and it was quite exhausting. Even things like trying to go to the loo because you've got this drip stand with these pumps. So she would wait until I was there to take her because of manoeuvring things and opening doors. It was easier if I was standing outside so she didn't have to worry about locking the door.

Interviewer: What I'm hearing is that you got a very different feel of this place than you had of the consultation the day before, there wasn't a tension here.

VA: Yes, that's right. Although the place was very busy, I suppose it reminded me a bit of A & E, that bustle of efficiency. The patients were in recliner chairs and it was calm, it wasn't anything like as bad as I had thought it was going to be. (Interview 3, 20 August 2013)

Overnight the gloom of the formal diagnosis was quashed by the quick start of the treatment. There was no time to worry or further anticipate what might happen. At the time we were just impressed by the efforts of the oncologist. It is clear however, from the surgeon's notes of the first Gynaecology Cancer Multidisciplinary Meeting (MDM), that the team were moved by Jane's plight. Under the heading *Clinical details* is the cryptic phrase "3C ovarian min, dreadful burden, neo A +/- primary" (MDM hospital record, day 30). Otherwise the form is simply a hospital note that accounts for a discussion about a particular patient, their disease and the treatment plan. The detail of who was present and what was discussed, is not recorded. Mattingly (1998) distinguishes between the recorded 'chart talk' of clinical detail which emphasis pathology and diagnosis and the discussion of patients' personal stories which have "no formal status as a vehicle for clinical reasoning" (Mattingly, 1998: 273). The awfulness of this particular woman's situation and its reality, is encapsulated by the expression 'dreadful burden'. It may seem unnecessary to ask who had the burden? It was most probably intended to refer to the burden being carried by a woman with an advanced gynaecological cancer but the term burden has other, quantifiable meanings in health care.

In 1990, the World Health Organisation (WHO) and the World Bank commissioned the Harvard School of Public Health to quantify death numbers worldwide and to take into account the impact of disease and disability on populations. The research was reported as the Global Burden of Disease Study.<sup>47</sup> The result was a single measurement termed the overall "burden of disease" (Murray & Lopez, 1996: 2). The study team used time as a common currency to determine the impact of disease or disability on what might have otherwise been expected in a healthy lifespan. Two key standardised measures were devised: the Quality-Adjusted Life Year (QALY) and the Disability-Adjusted Life Year (DALY). The quantification of health care interventions in terms of cost effectiveness was not new, especially not in the US where such services are not free at the point of delivery. The post-war interest in affluence and the subsequent attention to human relations in the 1960s, have been attributed as key factors to the rise of health economics (Robinson, 1986). The related term, Quality of Life (QoL) described as 'ubiquitous' (Fallowfield, 2009: 1) because it can be measured and defined in so many ways, making comparisons difficult. Nevertheless, in a systematic review it was found to be a helpful measure for improving survival outcomes in cancer patients when used as a prognostic indicator

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<sup>47</sup> See WHO Global Burden of Disease web site:  
[http://www.who.int/topics/global\\_burden\\_of\\_disease/en/](http://www.who.int/topics/global_burden_of_disease/en/)

prior to treatment (Montazeri, 2009). The clinical team with responsibility for Jane's treatment plan were also familiar with the concept through their local guidelines:

Treatment is not usually curative. ... The goal for healthcare professionals must be to ensure that where cure is not possible a woman can have a good quality of life with judicious use of surgery and chemotherapy. (SIGN, 2013: 1)

This seems to confirm the judicious nature of the treatment plan which was to try the chemotherapy protocol but it was known and accepted that even this was unlikely to be successful and that cure was impossible. Miracles were not discussed.

There are other ways of exploring the concept of burden in this study which go beyond health economics. At this point in the narrative, the burden of the disease for Jane and for me as her partner and carer, had not fully emerged. We were aware of the physical burden as the weight and girth of Jane's abdomen. It may be helpful to distinguish between the personal burden for the individual as the disease affects the physical, psychological, social and financial aspects of daily life, and the global burden as outlined above. However, this fall into the trap of reifying illness as a medico-scientific commodity which would then allow someone to distance themselves from the disease by claiming they are a victim of external forces (Bury, 1982). Viewed in this way, the ill person does not need "to accept fully the burden of responsibility" (Bury, 1982: 173). As a result of improving healthcare and the decline of infectious diseases, chronic illness is an increasing burden for healthcare systems and providers. More recently, the burden of treatment has been recognised as a feature of chronic illness:

... patients experience new and growing demands to organise and co-ordinate their own care, to comply with complex treatment and self-monitoring regimens, and to meet a whole range of expectations of personal motivation, expertise and self-care (May et al, 2014: 2)

The authors go on to propose a model designed to capitalise on the patient's social networks in the pursuit and support of patient-centred care. In Section 4.3 Finding, I noted that the dance had begun with the formation of Jane's social network, the basis of her support. Now, as we come to understand the burden of the treatment regime, so the complexity of the dance is realised. Jane summarises the first chemotherapy session and what would become a typical chemo day:

Chemotherapy is a fascinating process. I think perhaps some people are scared of it, because it's poison, and because it makes your hair fall out. But

it's the medicine, it gets rid of the cancer, it's what makes you better. The dialectic of toxicity, kill/cure, creation/destruction, is quite hard to get your head around. Remember when we were in Belgium in February and Parsifal had such an effect on us? One of the key themes is the healing power of poison, but we never thought at the time that this would strike home with quite such force. My drugs of choice is TaxolCarboplatin based on yew (taxus) and platinum. The day before the first session [we went] to the Botanics to commune with the yew trees (and maybe we'll get those platinum eternity rings after all...)

The chemo cycle starts in the middle of the night before when I have to take a massive dose of steroids (which make me rather bouncy, some might say aggressive although only towards my pillows, but are intended to prevent nausea) ... Then I sat in a reclining chair by an open window above a flower garden from around 11 until shortly before 5 while various fluids coursed through my veins (the yew and the platinum, interspersed with saline, antihistamines, steroids and various other things to counteract side-effects). It was a really interesting day, for the procedure itself, for the people also undergoing treatment, for the calm, kind, incredibly busy efficiency of the nurses. (Blog post 'Silver linings', day 44)

The first paragraph introduces two important features of Jane's personal philosophy and my interpretation of the path to the aesthetic experience of dying. I do not propose to discuss the latter point at this stage in the thesis as there is a detailed exploration in Part Three. What is noteworthy here is the use of opposites or polarities, and the relevance of symbols. Jane recalls our visit, when we were in Belgium, to a modern production of Wagner's opera *Parsifal*. She wrote a blog post at the time (six months before we knew of her illness) in which she recalls our first (and only) visit to the opera together:

There was no spear, no chalice, no cross in this production – so quite challenging to follow the plot with the central symbolism absent. There was a lot of veiling, hiding and camouflage, boundaries and bounds, sexual interplay and duality, ambivalence in the dichotomy of good and evil. The eternal feminine was starkly, barely and intimately central (das Ewigweibliche zieht uns hinan). (Blog post 'A night at the opera', six months earlier)

Her quotation is from the closing lines of Goethe's *Faust*, usually translated as 'The eternal feminine draws us upwards'. Conventionally this is interpreted as Faust's salvation but Jantz (1953) finds a deeper, more potent meaning that I doubt was lost on Jane. He argues that the entire play centres on the realisation of the symbolic essence of truth through the principle of what he translates as 'the eternal womanly' and defines as "the feminine principle of love, of

mercy and grace, which leads the spirit upward to the highest perfection” (Jantz, 1953: 792). Clearly, there is no certainty that in recalling her memories of *Parsifal*, Jane remembers her earlier insights but I suspect she does and draws strength as Gadamer (2004) suggests through an inner fusion of her understanding (of Goethe) and interpretation with the practical application of an actual text, that is *Faust*. She may well have reached a realisation similar to that proposed by Jantz:

The ‘Eternal-Womanly’, therefore, was unmistakably intended by Goethe to comprise in symbolic form the great creative continuity of life, birth and rebirth in constantly renewed forms, the ultimate resolution of death, destruction, and tragedy in new cycles of life, constructive activity, and fulfilment. (Jantz, 1953: para 804)

I suggest that she drew upon this interpretation in her understanding of one of the *Parsifal* themes, that of a healing poison. This is the Paracelsian notion that it is the dose that makes the poison or “the thing that harms is also the thing that heals” (Jung, 1992: para 373). In the blog excerpt two polarities are identified: kill/cure and creation/destruction. Both are highly relevant to someone undergoing a toxic treatment to *kill* by *destruction* that which the body has *created* although the possibility of *cure* was understood to be remote. The use of polarities was recognised by Jung in his interpretation of the *Parsifal* story:

Under the spell of Klingsor is Kundry, symbolising the instinctive life-force or libido that Amfortas lacks. Parsifal ... free from opposites, is therefore the redeemer, the bestower of healing and renewed vitality, who unites the bright, heavenly, feminine symbol of the Grail with the dark, earthly, masculine symbol of the spear. (Jung, 1992: para 371)

It is also worth noting the central themes of Wagner’s last opera which reveal a deeper parallel: suffering, pain, compassion and redemption (Kinderman, 2005).

Returning to the story, treatment has started and many adjustments are needed to the step sequence of our lives as we learn to accommodate the practical implications of chemotherapy. We return to Glasgow following the first session where Jane’s mother and our cats have to be indoctrinated in the new hygiene regime:

Interviewer: Okay, you say that we’re getting our heads round the various drugs and behaviours [referring to storyboard], and I’m wondering what behaviours?

VA: Well we’re now back through in Glasgow and so her body has been hammered by these highly toxic agents and we’ve got to be really careful



about infection. So we were both pretty good at hand-washing anyway but hand-washing has been taken to new heights. But it's not as simple as just the two of us, it involves her mum as well and that was quite difficult and we were on tenter-hooks that Jane would then catch something. We also had the cats and the cat litter and didn't want the cats bouncing around with stuff.

Interviewer: How did Jane get her head round this?

VA: Well she didn't really have to do too much because I just took over and instigated whatever hygiene arrangements needed to be done. What she did was to make sure that she washed her hands and she would avoid going to close to people. (Interview 3, 20 August 2013)

This extract illustrates the additional difficulties we both faced by not being, or feeling, 'at home' and the added anxiety of the effect the illness was having on others. Jane wants to protect her mother who is disempowered by my presence in the primary caring role. Feeling relaxed has become impossible even when asleep in the uncomfortable bed arrangements. The parallel activities of making our new home habitable continue but plans to decorate the entire flat ourselves are abandoned in favour of professional decorators. We decide to stay in a guesthouse for a few nights of relative comfort and to supervise flat improvements. However, the treatment regime and its necessary behaviours are compounding an already difficult situation:

Interviewer: And at this stage you're saying a bit about the family reacting strangely at times and mostly staying away.

VA: Well the message had gone out on the jungle drums that infection control was in place and that if they had a cold or anything like that they [her family] were to stay, well they weren't to stay away but they were to keep their distance. Her mum certainly went out quite a lot and it was really difficult for her because this was an awful thing that was happening to her daughter and it was hard to watch.

Interviewer: How did Jane react to them not really knowing what to do and staying away, that bit of tension around that?

VA: She found that quite hard because it was about finding a balance between understanding that somebody's at risk of infection and there are some simple measures that need to happen but that doesn't mean to say that people can't visit. I think because I was guarding Jane to such an extent that was possibly part of it as well. There was a slight feeling that the infection control was a good excuse, it made it easier for people who would have found it difficult to visit, to say oh well I've got a bit of a snuffle. (Interview 3, 20 August 2013)

It was a very difficult time for everyone and the repercussions within a family take time to settle. Where studies have been done these tend to focus on spousal response (see for example Wilson & Morse, 1991 and Hilton et al, 2000) or on family survival (Mellon & Northouse, 2001). This was perhaps simply part of an adjustment process where family members reflected on their positions in response to the shocking news. The treatment process is affecting Jane:

There was an overwhelming weariness, she wasn't sleeping particularly well, she wasn't comfortable in bed. Then all of this stuff had happened to her in a quite short space of time. She'd just completely been through the wringer, she needed to gather herself together. I suppose we had gone into the excitement of the treatment phase buoyed up not only by the apparent positiveness of the oncologist but also with the amount of steroids that she was given. (Interview 3, 20 August 2013)

And it is not just the tiredness from the treatment that is having an effect. We both knew her hair would fall out, warned by the oncologist, but neither of us are ready for the real impact:

I think within three weeks of her having the chemo, it started to come out. That was awful, that was really hard for her, she knew it would come out. There was clumps of it on the pillow and stuff in bed and it's one thing knowing it's going to happen, it's quite another thing watching it happen. So I cut it short but then within a few days it was getting really patchy and it looked a mess so I said maybe we just need to bite the bullet and get rid of the whole thing so that you've got a nice smooth pate. Her father had gone bald and so that was okay. I was very conscious of that person, of how she looked then, had gone. Her hair would never grow in the same again, she would never look like that again. She'd had beautifully thick hair, but that was it, gone. (Interview 3, 20 August 2013)

Despite being forewarned, the impact of chemotherapy-induced alopecia remains an unfilled challenge in clinical oncology (Roe, 2011, Paus et al, 2013). In a study of women with ovarian cancer, alopecia was seen to be an additional challenge following major gynaecological surgery and a further reminder of a likely early death (Jayde et al, 2013). Accepting changes to bodily appearance has been termed "embodying identity" (Koszalinski & Williams, 2011: 116) to account for the transition the individual must make from self denial to incorporation of the new physical self. Jane however, appears to take hair loss in her stride "We've cut my hair short in anticipation of things to come – it needed cutting, and felt a bit more in control of things to shorten it ourselves" (Blog post 'Portobello', day 47).

Three weeks later she has apparently adjusted to her new appearance and celebrates by publishing her hat design:

This summer's must-have fashion accessory is the chemo bunnet™. An exclusive range of limited edition headwear has been designed and created by Plenderleith Fashion House of Edinburgh. Handcrafted from delicate, soft bamboo and cotton blends, the chemo bunnet™ is sensitively coloured to grace the bald pate with poise and comfort for any situation inside and outside the home. It's worn just above the ears, eschewing the Benny from Crossroads look, and covers the whole head thus avoiding any potential confusion with the kippah. (Blog post 'Essential Accessorising', day 66)

Jane has re-invented herself as the woman not just coping with advanced cancer but, with a little self-deprecation, embracing the effects of the treatment on her body by playing with her appearance. This is the public image which she wants to convey to family, friends and anyone else who happen upon the blog; she has a tendency to use it to fend off enquiries from concerned colleagues. In private she does not say how she feels about her alopecia but I know not to ask. When her eyelashes and eyebrows go, she becomes upset and hates the bathroom mirror. Neither of us are good with make-up and although an attempt is made with eye-liner and eye-brow pencil, she looks like a clown. Efforts are promptly abandoned in favour of hair-free honesty, a reaction similar to the suggestion that some women react through provocation when "baldness is seen as the symbol of the cancer patient's new identity" (Rosman, 2004: 333).

By day 50, we have decided to move into the now painted and carpeted flat, and live through the disruption of the kitchen installation. Over the next fortnight, possessions and cats are brought from Glasgow, and the furniture arrives from storage in the Highlands. To avoid the trip hazards of unnecessary clutter, much of our belongings goes straight back into storage but now it is at least nearby. At the end of a blog post on the practicalities of living with minimal equipment and furniture, Jane describes her glabrous state:

I'm now magnificently bald, by the way, although some grey fuzz has started to reappear which looks and feels a bit odd. A bit self-conscious, I've been alert to people's reactions – some give me a big broad smile, some look away, most don't seem to notice. Being bald is only a stigma for women, of course. But as [my sister] says, rumour has it I'm too sexy for my hair. (Blog post 'Indoor Camping', day 62)

What Jane does not write about is the correspondence she has with her cousin's daughter who was studying biochemistry. It starts innocently following the email she sent to everyone regarding our change of address but soon becomes a frank discussion:

Cousin: I did a module in cancer biology last semester. How much do you know about what you've got?

Jane: I have a Stage 3 serous tumour which started on my left ovary (or fallopian tube, there is apparently some debate), has munched through most of my uterus and 'involves' the bladder and the rectum. I've learned a little about BRCA1 and BRCA2<sup>48</sup> mutations but mostly just from wikipedia. [The oncologist's] taken some blood for DNA analysis if he can include me in his study. Somehow making a contribution to research makes me feel a whole lot better. That much I know. I'd really like to chat to you about this, objectifying the condition also helps me to deal with it.

Cousin: I didn't realise BRCA1 and BRCA2 were related to ovarian cancer – I don't know an awful lot about them, except that BRCA2 is the most common genetic cause of male breast cancer, and that they're involved in DNA repair – as most oncogenes are. (Personal email, days 55 - 59)

This exchange is followed by a lengthy discussion on the finer points of oncogenes and genetic mutations. I am deliberately out at the time but Jane says it was helpful and good to catch up. I do remember that she was immensely impressed by her scientific cousin's knowledge and the intellectual quality of the discussion. This young woman was able to provide credible, scientific information early in Jane's illness and treatment when others either mollified (the gynaecological cancer clinical nurse specialist) or just did not know (much of this was new to me). I feel relieved she is talking to someone about her condition although not perhaps her situation. We continue our dance, still trying to master the steps but getting the rhythm:

→ Week before treatment visit GP for chemo bloods → Chemo session → Week after feel a bit grim → Next week feel better → Week before treatment visit GP for chemo bloods

Then a variation, a letter arrives instructing Jane to attend for a CT scan of her abdomen. The appointment will take an hour which seems a long time for a scan but the reason becomes:

A nurse came out and said that Jane had to drink this contrast medium which was a litre jug. Jane found large volumes of things quite difficult and she had to drink it within an hour. So she started to try and drink but she was getting overwhelmed by this volume of stuff. We had to work quite hard at keeping her calm, reassuring her that no she wasn't going to throw

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48 Breast Cancer 1 and Breast Cancer 2 — see Narod & Salmena (2011) for historical overview.

up. She really did struggle with drinking it all and there was a lot of clock-watching. Eventually she managed to drink all the stuff and went off for the scan. (Interview 4, 27 August 2013)

We are not warned that Jane needs to drink the litre of fluid prior to the scan but then I doubt if the staff can empathise with feeling full to the brim and then being asked to drink a litre, in forty minutes. It seems a cruel irony that in order to evaluate the progress of the treatment, another torture has to be endured. Jane stoically understands the need for the scan and the discomfort but it is a hard experience for us both. The result of the scan is reported within a few days, before the clinic appointment the following week but the oncologist calls one day after Jane has been for her usual blood tests. He is concerned that the spreading disease is in danger of affecting Jane's right kidney, the functioning one. My trump card, which saves Jane from an interim hospital visit, is the blood tests from earlier that afternoon. The oncologist is able to check the results and confirm that despite the scan report, Jane's kidney function is fine.

However, the clinic visit the following week was rather tense as I recall. It may seem trite to say that Jane wanted a good report but the actual meeting was difficult:

The oncologist broke the news, not particularly gently I felt, that the CT scan after the third chemo cycle showed that the tumour had not apparently shrunk very much. Certainly not enough for them to consider surgery at this stage. He asked if this news surprised me. I think I nodded, while actually it would be more accurate to say that it rather floored me. Because I had been feeling so much better, and stronger (and smaller, the swelling having reduced significantly), I was sure the chemo was working and that surgery would be scheduled soon. Instead [the oncologist] has proposed a new weekly chemo regime, which means a bit less of the chemicals at one go, but more often. For the next few months our weekly plans will have to be organised around blood tests and hospital days. As the doctor in the cancer unit put it, it's changing from a bazooka-type approach to a machine gun. (Blog post, 'A different mindset', day 98)

The report of the MDM meeting prior to the clinic session, affords another explanation for the oncologist's apparent abruptness:

This lady's case was discussed at the Combined Gynae Oncology Meeting and I saw at the clinic thereafter. As you know she has now received 3 cycles of three weekly Carboplatin and Paclitaxel chemotherapy for a grade 3 stage 3C serous papillary ovarian carcinoma. Previous laparoscopy had shown the disease to be extremely extensive and certainly inoperable at that point. Unfortunately the lady's CA-125 level has gradually crept up on chemotherapy having been 8967 at the start rising to 9184 after 2 cycles. In

terms of a percent change this is clearly minimal. Radiology from pre-chemotherapy compared to post chemotherapy suggested the disease has remained largely stable but that there is worsening hydronephrosis. Discussion at the Multidisciplinary Team revolved around the fact that this lady appeared to have very resistant disease and that we should change her to weekly Carboplatin and Paclitaxel. (Hospital record, day 86)

I suggest this was not the discussion that the team wanted to have but they were also aware that a good response to the chemotherapy was unlikely. Not only did the scan show a worsening of the disease, the CA-125 tumour marker was rising not falling. While Catt et al (2005) have reported that MDMs can be beneficial for both patients and health professionals, the emotional strain on the team, particularly its leaders (the oncologist and the surgeon) can also be an issue for some. Others have suggested that clinicians with high job satisfaction through status and research (Ramirez, 1996) develop a range of coping strategies to offset the stresses and strains of their jobs (Bates, 1982). However, there will always be difficult cases such as those affecting younger people who often present with advanced and therefore untreatable disease. The team had previously discussed the 'dreadful burden' of this particular case and now, despite three cycles of chemotherapy, the scan and tumour marker results indicated disease progression not remission. The oncologist's irritation can perhaps be understood as frustration at the impotence of the treatment and the likely impossibility of remission (Stiefel & Krenz, 2013). The oncologist's version of the encounter suggests a more positive mood:

When I actually saw the lady at the clinic she told me that symptomatically she felt much better since starting the chemotherapy with more energy and resolution of her abdominal pain. She admits some abdominal distension still persists. In terms of toxicity to chemotherapy the only major side effect has been alopecia. Fatigue was an issue after cycle 1 but this has decreased as time went on. (MDM hospital record, day 86)

In those first few weeks following the diagnosis, it was easy to be carried along with the rapid response by the health professionals to start treatment. Equally, as we learnt the new dance to our hope of remission, it was easy to push away the dark thoughts of reality. Now a much more vigorous dance is needed but I want Jane to start directing it, to make the decisions herself:

She had to take responsibility for what might happen to her and she needed to be in control of what was done. There would inevitably be some very difficult choices. I knew what the surgery would involve, that we weren't just talking about going in and taking out the bad bit, they would take out quite a lot of other bits as well which would result in colostomies and all

sorts of re-plumbing. The severity of the disease meant that she really did have choices about how much treatment she wanted. But she had to be the one to say. (Interview 4, 27 August 2013)

I want her to know how bad it is, to face reality as I see it but I sense she is not yet ready. Despite the difficult news, it is only a few days before we are back out enjoying life. Jane is feeling more energetic and enthusiastic than she has for some time. We indulge ourselves in the festival city of culture with visits to the theatre, art exhibitions and regular excursions to the botanic gardens. She is clambering up nearby hills, revelling in her ability:

This morning we climbed to the top of Allermuir Hill, the focal point of our living room view. Only 1619 feet high but all achievements are relative and I was very pleased to make it to the top and back down again, feeling stronger and more like myself with every step. (Blog post, 'Top of the view', day 89)

This particular walk is only three days after the clinic appointment and the realisation that the treatment regime needs to be more aggressive. Jane's response is to climb a mountain both physical and psychological, to get out into the world, to rise above the city and draw strength from a wider landscape.

### 5.3 *Turning*

The story continues with the adjustments to daily life and the new treatment regime. Following the review at the clinic I have been trying to persuade Jane that she needs to talk to someone about her situation. She has been clear from the outset that she does not want any psychological help despite offers from support services such as the Maggie's Centre. Eventually she concedes to visit a medical herbalist, a meeting that proves to be significant in many ways. Afterwards I note "Yesterday was quite cathartic and we have turned a big corner" (Personal diary, day 92). Yet a week passes before Jane describes the visit:

I've come to realise that chemotherapy is a rather blunt instrument. This realisation has led me to explore other ways of fighting this cancer besides the accepted medical model. I'd set a lot of store by [the oncologist] and the team doing that 'really good job with the chemo' they needed to do in preparation for surgery. I'd channelled a lot of my energy into believing that this was going to work, and to expressing my confidence in the oncology team as I projected an image of confidence and optimism to family, friends and myself too. This confidence has been a bit shaken, but sometimes a good shake is just what's needed. The wind in the trees shakes out the old, broken branches and dead leaves and lets in the light to the vital, growing

stuff at the centre.

I had a bit of an epiphany during the consultation with the herbalist. Actually it was a bit of a crack-up, or a breakdown. At any rate I started to cry, and once I'd started I had some difficulty stopping. I hadn't really had a good cry about the cancer, and as everybody (the herbalist, the nurse in the chemo ward for example) keeps telling me, these emotions are better out than in. Putting my energy into projecting a confident, optimistic front while keeping a lid on my frustrations and fears does not help my body to deal with the cancer. Some people think it's keeping a lid on things that causes cancer in the first place (oncologists think otherwise of course). At any rate I did feel the better of a good cry, and of being able (when I could speak again) to articulate my fears and frustrations. I was upset at myself for not responding as well as was hoped to the chemo. Like not doing as well as I think I should have at my chemo exam and somehow letting myself, and others, down. Old, engrained habits die hard. (Blog post, 'A different mindset', day 98)

Ten weeks after diagnosis, Jane has now taken ownership of her diagnosis and recognises she has been relying on the health care team to do 'the really good job with the chemo' while she passively complied with treatment and all its necessary intrusions. By looking out and into the new and interesting world of hospital-based therapy, Jane ignored her inner demons appearing to accept her diagnosis and be engaged with its treatment. I suggest an alternative explanation of post-traumatic stress disorder (PTSD):

... a response, sometimes delayed, to an overwhelming event or events, which takes the form of repeated, intrusive hallucinations, dreams or thoughts or behaviours stemming from the event, along with the numbing that may have begun during or after the experience (Caruth, 1995: 4)

It is not the event itself that results in the response but the failure to assimilate the experience at the time, that causes the disorder. A study of women with ovarian cancer found that while overall there was no real difference in the occurrence of PTSD than within the general population, there was an important emergent factor of an avoidant and disengaged coping style (Shand et al, 2014). This was associated with symptoms of PTSD such as substance abuse, self blame and denial. For Jane substance abuse is not an issue but self blame and denial are:

Recognising that it's not my fault is a big thing. Most cancer sufferers apparently think it is their fault, that the tumour is payback time for something they've done (smoked, eaten) in the past. Apparently too there is a strong correlation between introspective, self-critical personalities and cancer (again, this is not a correlation that oncologists would research or



recognise). (Blog post, A different mindset', day 98)

In truth, it was perhaps more of a delayed reaction than actual PTSD that Jane felt. Stacey suggests that remembering the traumatic experience, as in the shock of an advanced cancer diagnosis is “a route out of, not into, the experience. The survivor might thus move on from the trauma through a witnessing of the event, rather than a return to it” (Stacey, 1997: 16).

By recalling the experience of the diagnosis in the interview with the herbalist, Jane is able to reflect on it and accept its reality. Jane would have interpreted this as a *return enhanced*, as the interplay between acceptance and rejection. She is able to accept her diagnosis and prognosis when she returns to thinking about it as she recalls the discussion with the herbalist. Previously, she was able to reject the reality of her situation because others were dealing with it for her and taking responsibility. At first glance, it appears she has no choice but to accept the treatment plan. I feel she does have choices, however stark they might be: to have treatment, or not and to explore the alternatives.

Our experience of health care was completely different. Jane had only been to hospital as an out patient or visitor, enjoying good health until this illness. I was a nurse with many years of hospital practice. Jane had little familiarity with complementary and alternative medicine (CAM)<sup>49</sup> until she met me. I had been dabbling with various aspects for many years before settling on diet, yoga and health supplements. Consequently we believed ourselves to be better for the regime although a healthy diet and regular exercise are considered more than adequate. But any suggestions that there might be other, complementary therapies that could help Jane is met with refusal for fear of interfering with treatment. However, Jane reappraises her trenchant position after the cathartic meeting with the herbalist when it is suggested there might be something she could *do* to feel calmer when faced with difficult situations. It is on this basis Jane then agrees to see a psychologist to help her with some relaxation techniques:

[The psychologist] just talked to her about a visualisation and helped Jane to find something, a visual metaphor that she could use when she started to feel stressed or uncomfortable. What Jane chose was a rock and it was a rock that she could climb onto. So she might be in fast moving water but there was this rock and she could get onto the rock and then feel entirely calm. After she had this session she would talk about sitting on her rock or ‘I’m

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<sup>49</sup> The US National Center for Complementary and Alternative Medicine (NCCAM) differentiates between therapies which support conventional treatment (complementary) and those which are as *alternatives*. In the UK patients are less likely to engage with CAM therapies although those with breast and ovarian cancers are the most likely (Helpman et al, 2011, Molassiotis et al, 2005).

just going to get on my rock' and she could take herself to this place and be much calmer. (Interview 4, 27 August 2013)

Jane has not necessarily appeared passive in facing her diagnosis, yet it is difficult for her to actively engage in treatment. All she needs to do is ingest or be injected with the various drugs of the regime. But after the meeting with the psychologist, an aura of calm appears to have replaced what I had perceived as Jane's denial of her situation. Whilst this denial may have been a partial adaptation response (Goldbeck, 1997) it is only now that an actual adjustment has occurred. One possible interpretation could be that of cognitive adaptation theory (CAT) which proposes that threatening events or situations can be addressed through an adjustment process that restores meaning, control and self-esteem (Taylor, 1983). It is through illusion which "requires looking at the known facts in a particular light, because a different slant would yield a less positive picture, or the beliefs [that] have yet to yield any factual basis of support" (Taylor, 1983: 1161). A study of women with breast cancer considered the possibly detrimental effect of having an illusion disproved but concluded that CAT "views people as adaptable, self-protective, and functional in the face of setbacks" (Taylor, 1983: 1170).

More recently, similar conclusions have been reached and also questioned the continued reliance, at least in the US, on a model of adjustment for those dying of cancer that does not fully capture quality of life (Christianson et al, 2013). The authors refer specifically to the model proposed by Kubler-Ross with its five stages of dying: denial, anger, bargaining, depression and acceptance (Kubler-Ross, 1970). Writing in a compassionate style, her focus and emphasis was on the need for realistic acceptance of terminal illness. At the time it would have appealed to those working in the early days of the hospice movement when there was little guidance and few resources. She wanted those caring for the terminally ill to "take a good hard look at our own attitude to death and dying before we can sit quietly and without anxiety next to a terminally ill patient" (Kubler-Ross, 1970: 240). However, the model has been criticised for being too neat and tidy, too American and more a vision of the good death than a model derived from empirical evidence (Barry & Yuill, 2011). The success of her book, *Death and Dying*, led in later years to more personal criticism and claims of arrogant self-aggrandisement (Parkes, 2013). Yet, in the introduction to the 40th edition, the thanato-sociologist Allan Kellehear describes the text as "one of the most important humanitarian works on the care of the dying" (Kellehear, 2009b: vii). While there can be little argument that the text did, and continues to, facilitate dialogue

about death and dying, such a staged process-oriented interpretation of an individual's situation may be as detrimental as helpful through its notion of a 'right way' to die.

Returning to the narrative and the effect of Jane's visualisation training:

Interviewer: This isn't part of the storyboard<sup>50</sup> but it feels like a sort of balance has shifted between the two of you?

VA: Yes, it was almost as if she was more like her old self, she was back in control. I had had to take over for about three months and literally hold everything and although I still had to do that in a physical sense, it was down to me to run the household, she was now my queen. She was calling the shots, she was in control and that was a more comfortable relationship despite all the underlying discomfort of her illness.

Interviewer: But I'm getting a real kind of sense of when you said Jane had been carrying a burden and she put it down, that something had clearly shifted and had made room for other things.

VA: Yes, I hadn't particularly thought of it as that but I think that's right. Until that turning point, it was entirely the burden of the tumour and the carrying of it. She was physically conscious of it, she could feel it, she could feel what she described as this brick but then her focus shifted from the brick to the rock. (Interview 4, 27 August 2013)

This passage suggests that Jane, on learning her diagnosis and subsequent treatment plan, may have been in what has been described as uncertain open awareness:

... when confronted with bad news, the patient or family member disregards the negative aspects and holds on to the chance of a good outcome ... People in this context do not dismiss the possibility of a fatal outcome, but they prefer the uncertainty of not understanding exactly what is going on. They pick and choose in each message; hope is more important than a certainty of death. (Timmermans, 1994: 330)

Timmermans had intended to use awareness theory (Glaser & Strauss, 1966) in this introspective ethnographic study of emotional coping mechanisms employed by patients and their relatives when faced with information of terminal illness. However, the author's mother became terminally ill during the study resulting in an additional, powerful dimension to an early example of autoethnography. Timmermans (1994) refined awareness theory, the idea that knowledge of a terminal diagnosis is either closed or unknown to the patient, and possibly their

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<sup>50</sup> This may appear as the interviewer acting as researcher but I suggest she was following her brief to elicit the shared experience and prompting accordingly.

family, or open and known to all. His interpretation expands open awareness to three discernible types:

- Suspended open awareness: ignore the information
- Uncertain open awareness: preference for uncertainty, choose favourable messages, privilege hope
- Active open awareness: full acceptance of the message with appropriate actions

While Timmermans (1994) claims that the emotional shock of diagnosis requires its information to undergo adaptive processing before it can be fully accepted, Mamo (1999) argues that it is not simply cognitive information processing but the emotional effort in comprehending new knowledge that obscures awareness. Since the formal diagnosis, I had understood the implications of the disease but I also knew Jane remained in a state of hopeful optimism that the treatment would be effective. Hope is a ubiquitous concept in any discussion of cancer and life-limiting illness, as perhaps is optimism. Perhaps it is not unreasonable to surmise that people will react differently depending on their dispositional optimism. This can be defined “in terms of the favourability of a person’s generalised outcome expectancy” (Bryant & Cvengros, 2004: 232). In other words, an optimistic person will look on the bright side despite a gloomy diagnosis. Hope has been defined as “the sum of perceived capabilities to produce routes to desired goals, along with the perceived motivation to use those routes” (Snyder, 2000: 8).

However, in reviews of the concept of hope in the palliative care context, both Clayton et al (2008) and Kylma et al (2009) ignore Snyder’s work and cite a nursing definition of hope as a “confident yet uncertain expectation of achieving future good, which, to the hoping person, is realistically possible and personally significant” (Dufault & Martocchio, 1985: 380). While not unreasonable, this does seem devoid of self efficacy in attaining or maintaining hope. The hopeful person passively waits for something good to happen. In the context of a cancer diagnosis that would be cure or prolonged survival (Clayton et al, 2008). Snyder’s (2000) theory of hope is predicated on a trilogy of: goals (desired outcome), pathways (routes), and agency (motivation). This seems to be a more useful approach in the context of person-centred care. In a study of the actual use of the word ‘hope’ by dying patients, Elliott and Olver (2007) suggest that as a noun, hope is limited to the objective reality of the medical world, where there is no hope.

As a verb, action is implied, there is something to be done *by* and not *to* the patient. This positive interpretation provides the patient with agency to focus on life and not their imminent death.

The shift from passivity to active engagement suggested by this interpretation of hope provides an explanation for Jane's positive reappraisal of her situation. Publicly, Jane continues with her face-work (Goffman, 1955) using poise to counteract her embarrassment of being ill but occasionally her guard slips and she expresses her real feelings. In an email to the scientific cousin she reflects on the conventional treatment regime and her own views:

I am now – following discussion with the herbalist and consultation of quite a lot of research – back on my full programme of supplements. The medical profession in this country will not sanction many of these because they have not done enough double blind trials to be absolutely sure they do not conflict with chemotherapy. In the US they have done quite a lot of work confirming how complementary medicines actually support the chemotherapy. Much of the received wisdom from the medical profession is very tentative, they will not do or recommend anything outside NICE guidelines – the medics keep everything tight and rigid so they are in control. That's the thing that I found most difficult to cope with in the first few months of my treatment – being so scared of doing anything that wasn't officially sanctioned, following every instruction to the letter, in case I did something that made the chemo not work. I have come to realise that it's not because I took mushroom complex or ate yoghurt that the tumour didn't shrink very much – it's because it was a bloody big mass in the first place and chemotherapy is a very blunt instrument. (Jane's email to cousin, day 113)

The blunt crudeness of the chemotherapy is making its presence felt in Jane's blood and her haemoglobin had finally become too low for comfort. She had in fact complained of feeling a little short of breath when we were hill-walking one day but I thought it was the effort of trudging up a steep section. Although we are now settled in the flat and there is a rhythm to daily life, it does not always go according to plan:

Chemo day and we were late as we got snarled in traffic around the tram works. Heard yesterday Hb is down to 97 so they want to transfuse 2 units on Monday. Both a bit freaked by this but mutual resolve it's for the best. (Personal diary, day 108)

Being a blood donor had never been an issue for either of us and we had both been regular donors in the past. But giving blood is one thing, receiving someone else's is another matter entirely. My first reaction was that she should have mine but it is a different group

notwithstanding the practical and ethical issues. We both felt conflicted knowing she needed the transfusion but ambivalent about its provenance. The scientific cousin is at hand to discuss the issue:

Jane: I had to go back in yesterday to have two units of blood. Took about 5 hours. They've been threatening me with needing a transfusion since July and we had managed to keep the haemoglobin just above the red line until last week when it fell to 89. So now I'm feeling particularly perky today — and much better colour :)

Cousin: Glad the blood transfusion's done you some good, you were looking a little pale in one of your pictures but that might have been because you were tired, or in Scotland. What blood type are you?

Jane: My blood type is O+ so they didn't have much trouble with the cross-match. My Dad is O+ and Mum B+ and the great joke when we were young was that we'd have BO. They kept checking my temp every 15 mins yesterday to make sure I didn't have a reaction to someone else's blood. I had convinced myself it used to belong to a nice Edinburgh lady who never smoked or drank very much (didn't do intravenous drugs, or consort with hepatitis sufferers, or eat dodgy meat products, or have multiple sexual partners...) and on that basis I had no adverse reaction whatsoever. (Jane's email with cousin, day 112)

Despite searching the literature, no references have been found regarding the emotional aspects or indeed any others in terms of *receiving* donated blood. There is a wealth of evidence on topics ranging from the altruism of blood donation (Titmuss, 1971) to issues of organ donor identity and recipient indebtedness. Yet the blood transfusion episode is a struggle as another body boundary is crossed. The blunt irony of treatment that has destroyed perfectly healthy blood cells now demands alien blood to course through Jane only to be decimated by the next wave of chemotherapy.

## 5.4 Living

In the last story of this chapter, our lives continue to be dominated by a steady stream of appointments as we dance between the GP surgery, the chemotherapy ward and the x-ray department while also making excited preparations for Christmas. My brother and sister with their partners are joining us for a family celebration of closed awareness. We all know and tacitly understand it will be Jane's last. But before the celebrations can begin, Jane has more appointments, the first being at the surgery for a flu vaccination:

VA: One of the practice nurses said that because I was Jane's primary carer, I

had to have it as well. I vacillated and said that I wasn't really very sure. She just grabbed me and stuck it in my arm. So I was a mixture of beaten down and furious that she'd made me have it but I wasn't going to do anything that would compromise Jane.

Interviewer: Did that have any impact on Jane?

VA: Well she just laughed, somebody had got one over me. (Interview 5, 3 September 2013)

It has been suggested that carer performance may broadly fall into two types: combative and pragmatic (Newbury, 2009). For example, in a combative sense, a carer may feel angry and the need for control while a more pragmatic style would be to cope and deal with events. The archetypal response to a cancer diagnosis is that of a battle, something to be beaten, to conquer, to win against the odds. Previously, the great disease fear was tuberculosis (TB), borne with a resigned and romanticised dignity among the rich while being despised as inevitable amongst the squalid poor (Bourdelaïs, 2006). The account in *The Magic Mountain* (Mann, 2005) of isolated but luxurious care in a Swiss sanatorium is not atypical. Recognised as a contagion for centuries, it was not until the 1940s that a viable treatment for TB was found and subsequently largely contained with effective public health measures (Daniel, 2006).

While battling disease is not specific to cancer as HIV and AIDS has been fought and conquered, it was the Lasker Foundation who first found that declaring 'War on cancer' was a very lucrative strategy (DeVita, 2002). As a result, the implementation of the 1971 US Cancer Act was heavily funded by the Foundation. In its current publicity campaign and fund-raising strategy, Cancer Research UK uses the strap line "We will beat cancer sooner. Join the fight"<sup>51</sup> to marshall an army of volunteers and fund-raisers. These groups undertake many extraordinary sponsored challenges to raise money, often in memory of a loved one lost to cancer. Regrettably there is no space here to explore the economics of health research and the disparity in funding between, for example, cancer and dementia (Siddique, 2013). I suggest the language used in the US to raise funds for their 1971 Cancer Act has resulted in the continuing use of such combative terms in response to cancer, its research and treatment.

Returning to carer performance, Newbury (2009) does not reference an earlier study which explored the husband's experience of caring for a wife receiving chemotherapy (Wilson & Morse, 1991). Using interviews and grounded theory, a three stage model was developed from

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51 Publicity from 2015 website, see <http://www.cancerresearchuk.org>

suspecting something might be wrong (Identifying the threat) to actively participating in their wife's care (Engaging in the fight) to getting through chemotherapy (Becoming a veteran). The terms and writing style may now seem dated and gendered but the process of adjustment described is helpful in understanding the changing nature of an intimate relationship muddled by disease. This model seems to support Newbury's combative carer style which in turn supports the heroic female death as one of concern and emotional expression (Seale, 1995). However, it is the cancer sufferer who really needs a combative style:

The Canadian Cancer Society widely publicises the slogan, 'Cancer can be Beaten.' This implies that cancer is a disease that can be fought. This analogy of battling or fighting is an activity one must participate in if one is to win. Thus, fighting is a prerequisite to winning. A further implication in the slogan is: if one fights, then one can be hopeful of beating or curing the cancer. Thus, the fighting process provides hope. Finally, the slogan also places the onus on the 'person' to do battle and win rather than on the caregivers or the therapy. (Wilson & Morse, 1991: 83)

Despite being written more than twenty years ago, such bellicose language continues to influence the response to a cancer diagnosis by both the affected person and their primary carer. Initially, Jane knows there is a fight in progress but it is being done by the health care team, so her response is one of passive acceptance. In turn, her powerlessness is reinforced by the disruptive nature of the treatment and her inability to take ownership of the situation. It is only after the cathartic consultation with the herbalist that she takes command:

The really big thing is realising that while it's not my fault I have cancer, it is my responsibility to deal with it. My body has done this to itself – and only my body can undo it, or contain and control it. With whatever help I choose to give it – medical, chemical, herbal, dietary, and psychological. There are many ways up the mountain. Other people can help – describe the landscape, suggest routes, provide kit and provisions, accompany me for part of the way – but I take the path myself. Knowing this is tremendously empowering. I am not a passive victim, I am in control of my own recovery. (Blog post, 'A different mindset', day 98)

My role is unchanged and I continue to 'buffer' anything I perceive as a threat to Jane's well-being and now understood as a common care response:

'Buffering' was a process by which husbands filtered and reduced the stresses of day-to-day living to protect their wives. ... The buffering process involved two active components: constant vigilance and cognitive action. Constant vigilance consisted of watching his wife's response to



chemotherapy and her interactions with others. Cognitive action involved the interpretation of his perceptions, judging whether his wife was in a harmful situation and then planning an action designed to buffer. (Wilson & Morse, 1991: 80)

By now we have a regular routine when Jane goes for treatment. I was aware at the time that my behaviour went beyond just 'buffering' as I generally got between Jane and what ever might be going to be done to her. I thought of this as 'guarding' when, for example, I would walk slightly ahead of Jane, with my arm out in front of her. That way, I could fend off any unwanted collisions or people being too near to her space. But it is more difficult to buffer conversations:

In a really busy ward like a chemotherapy unit there isn't a lot of time but A [favourite nurse] would make time to come and sit. What was particularly special about A was that on one occasion she was sitting talking to us both and she said to Jane, 'you know we can't make you better' and we both said yes we knew. Actually she said 'you know we can't cure you' and we said yes, we understood that this was only going to shrink things, it wasn't going to kill everything or make the tumour completely go away. Nobody else really had those kind of discussions but I suspect A had sensed something in Jane about the extent to which she was coping with it. (Interview 5, 3 September 2013)

On this occasion I remember feeling awkward at the exchange but accepted it might be helpful for this particular nurse to be honest and frank with Jane. The breezy positivism employed by the majority of the health care team was a cause of frustration as we were both aware of darker realities. Nevertheless, the truthful sincerity was hard to hear:

Interviewer: What was the response to that statement of 'you know we can't cure you'?

VA: I think at the time we both just said yes we understood, we knew that but I found it quite hard. I knew that they couldn't cure Jane but nobody had actually said that. I did feel that they weren't being entirely honest with us and that part of Jane's difficulty in coming to terms with the seriousness of her situation was that she was being carried along by this wave of enthusiasm from the oncologists for treatment.

Interviewer: How did she respond to that statement from A. Can you remember?

VA: I don't think she said anything, I think there was just a look in her eyes that said that she knew, she didn't want to talk about it now. We didn't talk about it a great deal, as I remember.

Interviewer: With the nurses or with each other?

VA: With each other.

Interviewer: What didn't you talk about a great deal, the getting better bit?

VA: The not getting better bit. I think I tried very much to keep up this positive thing of making the most of what we had and the best of each day. We were just going through this process, this production line of chemo in the hope they would be able to do something in the Spring. (Interview 5, 3 September 2013)

Our preparations for attending a chemo session are meticulous and include not just the provision of respective lunches and snacks, but also Jane's apparel: lucky stripy socks and a humorous tee-shirt. Perhaps this particular nurse has noticed our 'performance' and the positive nature of our demeanour. Concerned that we do not appreciate or understand the seriousness of the situation, she decides to address the issue. This accords with Copp's finding that putting on a brave and cheery face could be "perceived as behaviour not expected of a person in her situation" (Copp, 1996: 195). Consequently, a more astute and compassionate nurse might use such an observation as a cue to explore the emotional and cognitive aspects of a patient's situation. By now we are in a relatively comfortable place as Jane describes:

That's three months we've been here now, and we are feeling very settled. [Veronica] remarked the other day that we have found contentment, which may seem odd given the health circumstances, but is a pretty accurate assessment of how we feel, and the life we are living. Tests and hospital visits are accommodated into work and play without governing or obsessing us. (Blog Post, 'Fair to Middling', day 115)

We have learnt the dance of the chemotherapy routine and mastered the shift in tempo to weekly sessions interspersed with blood tests and scans. Or so we thought. Jane's blood is now showing definite signs of wear and tear as the regular destruction of blood cells and the time interval between poisonings is insufficient for the cells to be replenished. Chemotherapy-induced myelosuppression is known to be the most common toxicity resulting from chemotherapy (Kurtin, 2012). Its effects can be obviated to some extent by the use of combination therapies as with the treatment protocol of Paclitaxel and Carboplatin for Jane. However, Paclitaxel is also known to carry a high risk of myelotoxicity. The general response to signs of such toxicity is to either delay or reduce the dose of the cytotoxic agents but this may also limit the therapeutic potential of the treatment (Kurtin, 2012). We are aware of the risks associated with chemotherapy but unprepared when myelosuppression inevitably occurs:

Interviewer: We're getting ready to go for the chemo again and then A [favourite nurse] phones to say platelets were low and you start off that by saying it was a bit of a weird day. What does weird mean?

VA: We'd got into a rhythm of one day a week for three weeks going for chemo. It started the day before with going for the blood tests at the GP surgery. The hospital saw that her platelets were low and [favourite nurse] said 'you need to come in early, we need to check your bloods and then it depends whether you'll get chemo or not'. So we went in to wait for an hour for the blood result to come back. I didn't want Jane to wait in [the ward] where everybody else was getting chemo, I wanted her to go over to the Maggie's Centre so she wasn't caught up in it. But she wanted to wait there. The result came back and the platelets were even lower than they had been the day before so there was no way she was having chemo. So you would think that was one week that I don't have to feel awful for two or three days but of course Jane interpreted that as she'd failed a test. (Interview 5, 3 September 2013)

In fact her reaction is similar to that previously when her response to chemo was poor and the regime was increased "Like not doing as well as I think I should have at my chemo exam and somehow letting myself, and others, down" (Blog post, *A different mindset*, day 98). Until this point we have successfully assimilated Jane's illness and treatment into the flow of our daily lives thereby offsetting any biographical disruption (Bury, 1982) and restoring a degree of harmony (Rasmussen & Elverdam, 2007). We know why a close check is being kept on the status of Jane's blood, but we are unprepared for the effect of 'failing' a blood test. For Jane it is traumatic as I note the following day "J a bit washed out after the angst of yesterday" (Personal diary, day 130). The physical effect of no cytotoxic treatment seems to be almost worse than actually having it. Bury's theory of biographical disruption has been further developed to accommodate a fracture to the narrative. A sense of well-being is felt when narrative form is equal to biographical flow or the continuity of daily life. However "maintaining continuity was draining: exhaustion precipitated fracture and thus need for external help to restore continuity" (Reeve et al, 2007: 178). For Jane the continuity of the chemotherapy narrative is disrupted by the failed blood test and she feels 'exhausted' and needs my support to recover.

The following week there is another CT scan and on this occasion "all went well – not quite such an ordeal this time" (Personal diary, day 139). Jane knows what to do and is better able to pace drinking the litre of contrast medium. There has also been some reduction in her abdominal swelling so the additional volume does not cause so much discomfort. We then discover an

aspect of the intensive chemotherapy regime we did not appreciate: failing a blood test means a week is missed and not just postponed. We arrive for the unscheduled session the following week only to find we have both misunderstood the process:

I knew that we hadn't done something wrong but it was such a disappointment for Jane. She did have to psych herself up for the chemo, I knew that. It was a performance, it was an ordeal because there were such swings of being high from the steroids and then just the tiring nature of sitting still for six hours and having all this stuff in you. Then the feeling of everything having stopped the next day and then the feeling you've got bad flu. (Interview 5, 3 September 2013)

In this situation it was neither biographical disruption nor temporal discord that was the issue but a failure to understand the "ruling relations" (Smith, 2005: 10) of the treatment regime and hospital procedures. We were overwhelmed with treatment leaflets, guidelines and cancer charity pamphlets. Despite our mutual capacity to understand much of this information, we had both failed to grasp the nuances of this particular dance. In response I attempt some buffering behaviour (Wilson & Morse, 1991) "had fish fingers for tea to cheer her up" (Personal diary, day 143). After the scan there is a follow-up visit to the oncology clinic but on this occasion there was a different consultant, a cheery woman; smiles all round:

Interviewer: Did her gender make any difference?

VA: I'm not sure, she talked about had we looked at the Ovacome site because she had been the medical advisor for that and I think we both said no because neither of us found these cancer support sites particularly helpful. But she was very enthusiastic and I think Jane said she would then have a look at it. Whether her gender made any difference, I think I wanted it to but it didn't.

Interviewer: I wondered, was there any sense from Jane that things might be improving, any change in symptoms or anything like that, was it possible for her to notice?

VA: I think she was wary because she had been feeling better the last time only to be told that the chemo wasn't having that much effect and so she was a bit more guarded. (Interview 5, 3 September 2013)

The scan report is unequivocal:

When compared with the previous recent scan, there has been a definite reduction in the volume of the ascites. However the nodal metastatic disease and the pelvic tumour bulk mass appear similar in size and extent, although

this is difficult to quantify, particularly in the pelvis. No new disease sites seen. (Hospital CT scan report, day 140)

The improvement is that there is less fluid in Jane's abdomen, which she has noticed but in reality the chemotherapy had not affected the tumour; growth had been halted but not reduced. Nevertheless, the oncologist is keen to continue with the chemotherapy and for a review by the surgeon. Jane now takes a more active interest in her health:

I started to feel quite strongly – and conversations with many other people backed this up – that my body was telling me it would cope much better with the side-effects of the treatment if I gave it a bit more support. In the US, the use of complementary medicine alongside chemotherapy (not as an alternative) is increasingly supported. There's growing evidence that many vitamins and supplements not only help to counteract the side-effects, but can potentiate the primary effect ie killing the cancer.

So I've been taking lots of carefully researched and selected vitamins and minerals. That's when I started on weekly chemo. It's also when tests indicate the tumour really started to shrink. So far so good. Fresh air and exercise continue to be vital strategies. I'm a walking biology lesson, fascinated by my weekly haematology and blood chemistry print-outs. I often wish I could discuss this with my Dad, I think he would have enjoyed that! (Blog post 'Coping with Chemo', day 159)

Jane's comment "when tests indicate the tumour really started to shrink" refers to the tumour marker CA-125 which had been measured regularly since diagnosis. In the previous chapter, its continued rise after treatment started was noted but now it was falling. This finding is not in itself unusual as the marker is a difficult and controversial indicator, with up to 50% false negative results (Marcus et al, 2014). The test involves the detection of a protein in the blood which is secreted by ovarian cancer cells; in simple terms, if the tumour is active, the protein will be exuded. While Jane interprets the marker's fall as the tumour shrinking, the CT scan shows otherwise. The tumour is not shrinking, it is merely dormant.

Over the next few weeks the dance between the GP surgery, the chemo ward and the rest of our lives continues uneventfully. Jane's blood profile is closely monitored and although borderline, she receives a complete three week cycle. Preparations for our Christmas visitors progress and I create a bedouin tent-come-spare room in the attic. Another review meeting is scheduled, this time with the surgeon as promised by the woman oncologist at the previous clinic meeting:

Interviewer: So you went for an audience with the surgeon, now that's a very particular word so how important was this meeting?

VA: Well it was quite important. This was the first time Jane had seen the surgeon since the initial diagnosis.

Interviewer: So you say that this was all a bit strange and uncertain [referring to storyboard] so what was happening for you in this meeting?

VA: We were starting to be aware that there was a big question mark over whether surgery would be possible. The surgeon had always been very clear he wasn't going to go in and just start rummaging about doing stuff if he wasn't confident that he wasn't going to make Jane worse. So it was partly as a kind of reassurance that we must continue with the chemotherapy.

Interviewer: When you say reassurance, was he reassuring you or were you being reassured, I mean?

VA: Well I think that was what was supposed to happen but we weren't really reassured because I think we were trying to get straight answers and in the end he [the surgeon] just printed off the scan report and gave it to us. We didn't believe the oncologists because we would get a copy of the blood results from the GP and we knew what the tumour marker, the CA 125 was. We knew how much it was coming down or not and it wasn't falling anything like as fast enough, as it should've done and they would say to us 'oh it's only a number, it doesn't matter'.

Interviewer: Okay, and he gave you the scan report?

VA: Yes, he printed it off.

Interviewer: So did he discuss it with you or did he just give it to you?

VA: Well he said it's difficult to know. Basically the scan report says not much has improved, there's a bit less fluid but there doesn't appear to be much shrinkage. (Interview 5, 3 September 2013)

At the time of the interviews I did not have access to Jane's health records and believed that the referral to the surgeon was made by Jane's usual oncologist. It was only when I saw the records that I realised it was the woman oncologist who had made the referral. It is difficult to know how or why this made any difference but I sensed a certain frustration for the surgeon. Clearly the tumour had not shrunk and it was most unlikely he could do anything surgical but by giving us the scan report, he could at least be completely honest. We had been trying to get straight answers to straight questions both when Jane attended for chemotherapy and in discussion with the clinical nurse specialist (CNS). Whoever was asked in the oncology team always made light of Jane's situation and refused to be drawn on the tumour marker results.

It was not that we did not trust or respect the oncology team, we knew they were doing their best in very difficult circumstances but we needed the candour of the surgeon. He recognised this and trusted us to cope with the stark reality of the CT scan report. We knew from his energetic reaction to Jane's condition when they first met that he would do anything he could to make her better but only if it did not make her worse. Long gone were the days of going in and taking out as much of the bad bits as you could and then re-plumbing whatever was left and other ghastly memories. His feelings are clear in his letter to Jane's GP:

This patient was reviewed today. She has had minimal response in her CT interval scans and a fairly partial response to her CA-125. However, she is young, slim, very fit and we will organise a diagnostic laparoscopy at the beginning of January to determine whether she is surgically operable, however, I have feeling that this will probably involve the colorectal surgeons and possibly involve the urological surgeons.

I will take this opportunity to write to [colorectal surgeon] and ask her if she has any free dates for a joint procedure which will involve probably most of a morning or an afternoon list and possibly the formation of a colostomy or a ileostomy of which the patient is fully aware.

Ps: Dear [colorectal surgeon] This patient is absolutely delightful, she is young, she is certainly fairly majorly compromised with her current underlying ovarian cancer and I would appreciate if you could perhaps consider a joint procedure in early February for a fairly extensive mid line laparotomy and debulking procedure. (Letter from surgeon to GP, day 175)

My recollections are a further illustration of the ongoing issue of awareness, first discussed in Section 5.3 *Turning*. The surgeon confirms that Jane is fully aware of her condition and of what to expect from surgery. His interpretation of the response to chemotherapy is 'minimal' from the CT scans and 'partial' in the CA-125 results. His findings can be contrasted with the woman oncologist's letter to him, where she notes:

I met with this lady following the MDM on behalf of [usual oncologist] and clinically she is feeling much better indeed. She feels her abdomen has become a lot less distended and that she is eating well and there is less pelvic pain. We plan to continue with a further two months of the weekly chemotherapy, but would be grateful if you could see her in the interim to discuss possible surgery thereafter. We appreciate that this may not be possible. She may need laparoscopic assessment again, but also appreciate that surgery, if it does go ahead, will require some co-origination. (Oncologist letter to surgeon copied to GP, day 149)

These different styles in interpretation and in the encounters we had with the clinicians confirm Furber's findings in her doctoral study of the exchange of information in the advanced cancer setting. Doctors use a variety of styles to give and discuss "sharing uncomfortable news" ranging from "fudging the truth" to "mutual understanding" (Furber, 2010: 199). For us, the oncologists tended to fudge while the surgeon engaged in mutual understanding. I do not want to appear overly critical of the oncology team but we did have a sense of being played between the two clinical specialties, especially when the surgeon had expressed a slight frustration at being asked to review Jane's progress. We had the sense that he had made his views clear in the most recent MDM having referred to the 'dreadful burden' in the first MDM. Initially the lead oncologist gave a frank account of the discussion at our first meeting which he reported in his letter to the GP "The lady and her partner were already well up to speed with the situation and the precarious situation that she is in" (Oncologist letter to GP, day 37)

Now this awareness seemed to have waned and the focus has shifted from the disease itself to Jane's clinical appearance, emphasising the positive 'she is feeling much better indeed'. But this upbeat response was written by the woman oncologist, who does not know Jane so well as the lead oncologist she usually sees. There is a frustratingly gendered issue here: the men (the surgeon and the usual oncologist) were "telling it straight" while the women (the other oncologist and the CNS) were telling it slant (Long, 1999: 37). Judy Long took the idea of women putting a slant on telling something from an Emily Dickinson poem:

Tell all the truth but tell it slant  
Success in circuit lies  
Too bright for our infirm Delight  
The truth's superb surprise  
As lightening to the Children eased  
With explanation kind  
The truth must dazzle gradually  
Or every man be blind (Dickinson, 1976: 506, 1129)

This was the 'explanation kind' for the 'truth must dazzle gradually'. Yet what we wanted was male directness and not just information which we then had to frame and reach conclusions for ourselves (Borrelli, 2002). It would be unfair to criticise the oncologists for trying to retain



optimism in the face of what might otherwise be perceived as a hopeless case. Nevertheless it is notoriously difficult for clinicians to get the balance right over time and in each patient encounter (Innes & Payne, 2009, Furber et al, 2014). Our situation though, was subtly different from the encounters discussed and reviewed in these studies. We were fully aware of Jane's situation but were having difficulty reconciling the enthusiasm of some members of the oncology team with the empirical evidence of the poor response to treatment. Another interpretation could be that the women health professionals felt they recognised in Jane a need for a slant which was more important than my demands for straight talking. If I was blind to her needs, they were not, she needed time to assimilate the truth.

We do not dwell on this sorry state for long as Christmas and the arrival of our visitors is fast approaching. Time for some mutual face-work (Goffman, 1955) and a group hug from the circle of love of our nearest and dearest. Jane continues to have chemo but also needed another blood transfusion. The actual day everyone is scheduled to arrive is also a chemo day. However (as luck would have it?), the hospital phone to say Jane's platelets are borderline and she needs to go in earlier to have them rechecked. I note the complicated dance for the day:

Logistics day – flights on time so dropped J for bloods then to airport. [Sister & her husband] fine, back to [hospital] to collect J. Not long back when [brother & girlfriend] arrived! [Hospital] phoned – platelets no change so no chemo. Then GP phoned – muddle with the marker – it's going back up – not so good :( (Personal diary, day 192)

When asked about this episode, I recall:

Our own GP had phoned to ask how Jane was and to say she was sorry that the tumour marker had started to go back up. I just remember standing in the kitchen and saying to my sister, that was it, it was going in the wrong direction and we'd given it our best shot but it wasn't working as we'd hoped but that it was really important that we made the best of everything for Jane. And Jane understood, just as I did, that this wasn't good news but I think she just wanted to park it. She still had the prospect of the diagnostic lap being done in the Spring and everybody had just arrived and she just wanted to enjoy everybody's company and forget about it. Enough, there was nothing we could do then and what we could do was have a good Christmas. (Interview 6, 10 September 2013)

This polarisation of the joy of the family arriving and the dismal news from the GP was difficult for us both to bear at the time. We never understood why the GP decided to call and there is no mention of it in Jane's primary health care record. It was just one of those unfortunate incidents

which was meant with the best of intentions but was also ill-timed. Equally, the timing, while not perfect, was almost fortuitous as it did galvanise everyone to make every effort for a harmonious celebration:

It was, we generally decreed, the best Christmas ever. [We] had resolved when we came back to Scotland in March that we would have a wee cosy place where [my siblings and their partners] could come and we could all be together for Christmas. The plan worked. The circle of love came home. It was great. (Blog post 'Festive Family Favourites', day 212)

## 5.5 *Summary*

This chapter has recounted and analysed the treatment phase of the Illness Period. The initial enthusiasm of the quick response by the health care team has ended with the disappointment of the chemotherapy failure being offset by the joy of a family Christmas at home. The next and final chapter in Part Two, *The Last Waltz*, relates the gradual decline in Jane's physical well-being and culminates with her death.

## 6 The Last Waltz

### 6.1 Introduction

This final chapter of Part Two: The Dance to Death details events in the last five months of the Illness Period and covers 144 days, nearly five months. There are three stories: Reviewing, Part[y]ing, and Dying. It begins with the final chemotherapy session and another CT scan.

### 6.2 Reviewing

The Christmas Eve news that the tumour marker is rising once again gives renewed enthusiasm for the last chemo session. However, the destructive effect on Jane's blood profile has now spread to the neutrophils, a type of white blood cell responsible for fighting infection and reducing inflammation. The clinical team are reluctant for treatment to proceed but realise its importance for Jane as revealed in an email from the oncology registrar to the consultant. At the time we were unaware of the efforts to give as much treatment as clinically possible:

Hi – Jane is on cycle 4 of weekly Carbo/taxol and has only managed day 1 because her platelets have stagnated between 70 - 81. Her Ca125 has gone up this week. She is worried about the fact that she will not have had chemo [for a fortnight]. I am concerned that her Ca125 has turned up. She is keen for 1 more chemo at least next week and I thought that may be reasonable. I hope she can be treated next Thursday with a dose reduction in carbo. (Oncology registrar email, day 192)

Despite the gloomy realisation that the treatment is not working, there is another abdominal CT scan due before the next appointment with the oncologist. On this occasion it is at another hospital albeit in the same group, nevertheless the protocol is different. A package arrives in the post with a bottle of contrast medium and instructions, Alice in Wonderland style, to be drunk thirty minutes before attending. The hospital is in a neighbouring town necessitating an adventure to find it, the car park and the x-ray department. The difference between the two approaches for the same procedure is unclear:

Jane duly drank the [contrast medium] and it was only about half a pint, nothing like as much as she normally had to drink. So we found the x-ray unit and it was a much smaller place and there was no waiting room full of people trying to drink these great jugs of aniseed flavoured stuff. She didn't have to drink any more, it was all very quick and efficient, and we said we didn't understand why the procedure was different. They said that was how they did it there and they didn't have a waiting area as they do at the [usual hospital] and so they couldn't have people there for an hour before with jugs

of stuff. I thought, well it's much nicer this way but I think it's to do with compliance and making sure that people actually drink the stuff. (Interview 6, 10 September 2013)

We are puzzled by the difference in the procedure although Jane is just glad there is less to drink and that it is over quickly. For me there is a grumbling frustration as to why, when the health care team know how ill she is do they exacerbate her discomfort by making her drink more contrast medium than clinically necessary? In Section 5.4, when we failed to understand the temporal detail of the weekly chemotherapy cycle, I suggested that Smith's (2005) 'ruling relations' were evident. To really explore the issue of the impact of hospital procedures on patients' lives would need an institutional ethnographic study. Rankin and Campbell (2009) claim that the neoliberal agenda with its emphasis on efficiency and effectiveness has led to the subordination of nurses' judgement. This subordination is manifest in the "theory-practice gap" (Rolfe, 1998: 673) where there is a crisis of confidence in professional nursing knowledge. In this situation a nurse might have realised that Jane would have difficulty accommodating a large volume of liquid and raised the issue with the radiologist who could have recommended a reduction without detriment to the efficacy of the scan. This would demonstrate a recognition by the nurse of scientific knowledge (head) regarding the scan, personal knowledge (heart) of the patient, Jane, and the nurse's experiential knowledge (hand) about such situations (Rolfe, 1998). However, the x-ray department nursing staff are focussed on the efficient throughput of patients and ensuring work proceeded smoothly. The idea of personalised patient care is lost in the "contingent embodiment of the universal" (Frank, 2001: 358) where the individual needs and nuances of each patient are subordinated into a generalised operational mode.

The hospital visit is soon forgotten as we celebrate Hogmanay, gathering in the kitchen to watch the fireworks and toast the new year. I abandon my daily diary feeling it would become a painful burden to record Jane's dying. Instead Jane decides to note the best thing that happens each day, her second entry reads "Afternoon at home knitting, listening to Parsifal. Very calm" (Jane's diary, day 202). Then it is time to take the Canadian contingent (my sister and her husband) to the airport for a difficult parting as Jane notes "Such sweet sorrow, agreed they will come back in September and we will go to Islay for my birthday" (Jane's diary, day 210). We all know it is most unlikely this promise will be kept but all is not yet lost and the second laparoscopy is yet to come.

At the next clinic appointment the lead oncologist is quite upbeat:

I saw this lady at the outpatient clinic today. Her recently performed CT scan shows a further response to therapy. The lady's CA-125 level has essentially continued to fall throughout her treatment. The interpretation of the CA-125 levels is slightly complicated by the fact that the assays have been performed at two different hospitals but there has been a steady fall until [the previous month] (Nadir 2049) and a very small rise [in the most recent] sample (2080).

The lady herself is feeling extremely well. She has lots of energy and is still climbing hills and using her exercise bike. The lady tells me she has a date for a diagnostic laparoscopy and if it appears that her disease is operable then she will proceed to surgery as a combined procedure with the Colorectal surgeons and possibly the Urologists. (Oncologist's letter to GP, day 212)

For some reason we have a copy of this letter and it is quite helpful. It provides some resolution to the confusion regarding the CA-125 results and it reminds us of the possibility that any surgical procedure is likely to result in bowel resection and the need for a stoma. However, Jane finds the idea of a colostomy abhorrent despite my efforts to reassure her that we will deal with whatever happens. But she is encouraged by her 'good report' and does not want to dwell on the negative aspects of surgery should it indeed prove possible. Our focus for the past few weeks has been on the laparoscopy which the oncologist wants to assess the progress of the treatment. This is in addition to the CT scans and the CA-125 results which seemed to indicate there was little reduction in the size and extent of the tumour. Jane attends the same unit she was in six months previously as an emergency. This time it is relatively calm and certainly planned. The most memorable part of the episode for me, is Jane being prepared for and then wheeled away in her bed to the operating theatre:

Interviewer: The next entry [in the storyboard] is the actual diagnostic laparoscopy and what was the hope for Jane from this?

VA: We had to be there for eight o'clock in the morning and she was to wait in one of the single rooms. Quite a fuss was made by the staff about this room and it certainly looked a little bit different because it had lots more lights and wood panelling at the end. It was apparently the room that had been prepared for the former prime minister's wife to be delivered of a baby. Jane was very taken with this room and it went along with treating her royally, so we had a laugh about that. Then the surgeon came bouncing in to consent her for the laparoscopy and he said that there was a possibility that he would have more time on the list and he might as well consent her for the whole thing. So we said what did he mean? If he thought that he

could resect the tumour then he would do that so she was consented not just for the diagnostic laparoscopy but for the total hysterectomy and everything else.

So there was this overwhelming situation of thinking for some reason he was suddenly going to be able to do something and you get caught up in that. They eventually came to take her to theatre and I can still see her clearly, sitting up in bed with this huge grin on her face, she can't see because they've taken her glasses but she thinks they're going to fix her. I felt as though I'd been stabbed because I knew they couldn't fix her and yet there's that sliver [of hope] that maybe, just maybe he's going to go in there and think 'after all I can get this out'. But that cut right across all of the stuff that had been said previously about if they are going to do something it's going to need, at the very least, the bowel specialists but probably the urologists as well. Suddenly, he's a magician, he can do the whole thing. It was just awful, absolutely awful.

Interviewer: Did you and Jane have time to talk about that before she went away?

VA: A wee bit, I remember saying you know the chances are very slim, it's not likely, and if they do do something you going to wake up with other bits attached to you and stuff and she knew all that. But it's like somebody offers you a lottery ticket and says that there's a one in ten chance of [your number] coming up. This was a one in a million, the odds were appalling but I suppose from her point of view, going to theatre with a sense of elation was quite nice and that's certainly how she looked. For me it was just another gut-wrenching session and then a few hours of worrying about what was going on. (Interview 7, 8 October 2013)

There is no radical surgery and the reality of what the surgeon actually saw through the laparoscope is clear from the operation note:

Unable to fully visualise pelvic organs, partially mobile uterus but fixed left ovary. Utero-vesical peritoneum obliterated by disease. Mod amount of ascites. Widespread miliary disease in pelvis, pelvic organs stuck. Tumour in omentum, Port site mets palpable. Not surgically resectable. Diaphragms covered, porta hepatis involved. (Hospital Operation Note, day 232)

The operation note is almost unchanged from the original at the time of diagnosis:

Unable to visualise pelvic organs, fixed pelvis. Utero-vesical peritoneum obliterated by disease. Large amount of ascites. Widespread miliary disease in pelvis, pelvic organs stuck. Tumour in omentum. Not surgically resectable. Diaphragms covered, porta hepatis involved. (Hospital Operation Note, day 22)

The main difference now is that there is tumour growth at the port site of the previous laparoscopy. Once Jane has recovered from the anaesthetic, the surgeon comes to see us and we have a candid discussion about his findings. He suggests that if the oncologist has some magic chemotherapy and can get the tumour marker below 1,000 then he might be able to do something. He seems so desperate to try that he cannot bring himself to say to us what is stated in the operation notes on both occasions: the tumour cannot be removed by surgery. Jane notes in her diary “Had diagnostic lap – didn’t need to stay overnight. Came home for macaroni cheese & choc ice & cuddles” (Jane’s diary, day 232).

It is during this time that my sister sends an email with a picture of herself holding her print *Les Deux Solitudes* reproduced in the Acknowledgements of this thesis. We were familiar with the single image of the dancing woman having had an earlier version of the print hanging on the wall at home for many years. But this print with the woman moving through light and dark, in shadow and shade, seemed to capture something about our situation. In my reply to her email, I comment on the progress regarding an appointment for a review with the oncologist at the outpatient clinic:

No news here yet – Jane phoned yesterday to be told it might be next week and there was no urgency if she was feeling fine! Well yes she is but we don’t want to lose the momentum if there’s still a chance they can operate. (Personal email, day 238).

We seem to be clinging to “the magical power of treatment” (The, 2002: 128) and the surgeon’s idea that the oncologist has some magic chemo:

Interviewer: And you talk about not losing the momentum, what was that momentum?

VA: Just the momentum of thinking something was going to happen, keeping Jane’s strength and spirits up, trying to maintain her nutritional state, trying to maintain her level of fitness if she was going to have something done. Part of what had carried her through chemo was that she was working towards something that was going to have some sense of success in terms of treatment. That door was closing, but the surgeon had left it ajar and it was up to the oncologist to close it and so we needed to know. Was he closing the door, was that it or should we keep on trying. (Interview 7, 8 October 2013)

In due course, we attend the oncology clinic, a fortnight after the laparoscopy. The biopsies taken during the laparoscopy confirm Jane has ‘metastatic high grade serous ovarian carcinoma’

and that her CA-125 has started to rise. We have an honest discussion with the oncologist which he alludes to in his letter to the GP:

In terms of symptoms she describes more discomfort/twinges over the last couple of weeks but these only last for seconds. She also feels slightly more distended and has noticed masses around her port sites. We had a discussion today regarding the situation. I felt that a few weeks off chemotherapy would benefit the lady even though her disease is clearly slowly progressing. She knows that the disease is incurable and feels that quality of life is an important issue for her. (Oncologist's letter to GP, day 246)

The final sentence is evidence of Jane's prognostic awareness (Innes & Payne, 2009) and what matters to her. Some other less toxic (than chemotherapy) treatment options are mooted but their availability is dependent on further genetic tests. In her diary she writes "Hamamelis bright yellow against blue sky in the Botanics this afternoon" (Jane's diary, day 246). She does not dwell on what cannot be fixed or changed, choosing to focus on the bright, the beautiful and optimistically reflected the following day:

My lovely oncologist, who, lovely as he is, is not able to offer a ready solution to my current problem. The tumour is too large, and too widespread, for surgery to be an option (certainly not at present, and probably not at all). Additional chemotherapy is unlikely to have any positive effect on the malignancy at present either. [He] is investigating whether my tumour might respond to Tamoxifen, which is used primarily to treat breast cancer, and also my eligibility (in pathological terms) for a new gene-based drug trial. In the meantime, we have lots of trips and treats planned. We're getting through the initial list of 'things to do in Edinburgh', but there are plenty more to keep us amused. Family and friends in the West continue to offer love and support. Team Canada is onside, and reconciled (we hope) to a continuing schedule of away-only fixtures. We'll get cycling in the bulbfields this Spring. Everything is going to be alright. (Blog Post, 'Everything is Going to be Alright', day 247)

We spend the next fortnight going for long walks, Jane enthused and exhilarated with the effort. Then back to the outpatient clinic hoping to hear there are other treatment options. The oncologist is kind but does not prevaricate. There is a one in ten chance a particular genetic test will suggest a new biological agent can be tried but the reality is there are no more treatment options. We raise the possibility of a few days holiday in the Dutch bulb fields; he looks aghast and mutters that we would need to be 'maxed out on insurance'. We hear this and abandon such ideas. The situation is clear in his letter to the GP:



I saw this lady at the out-patient clinic. She was describing increased abdominal distension and dyspnoea which was getting worse on a daily basis. She also describes early satiety. Physical examination today revealed tense ascites with obvious shifting dullness. I discussed the fact that the lady's ascites had already recurred and we [will arrange] for the lady to be admitted for drainage of ascites.

We discussed the fact that unfortunately future therapeutic options would be limited (the rate of progression of the lady's disease following what is essentially our best chemotherapy regimen makes me fairly pessimistic about the chance of eliciting a response to other cytotoxic agents). The lady understood this discussion. If she did push for a trial of another agent then I could certainly discuss this with her. (Oncologist's letter to GP, day 260)

The treatment door is firmly closed, this is now the turn to face death. Jane is swelling and ageing fast. Fluid has accumulated in her abdomen to such an extent that the most basic of life functions, breathing and eating, are impeded by the pressure and volume. Her movement is restricted by the weight and girth of her distended belly. Her legs have swollen as the fluid finds other places to fill. In her diary she writes "Bob and Aggie [our cats] on either side of me on the couch, tranquil, beneficent, guarding" (Jane's diary, day 258). She is neither down nor out. In this stark reality, living must now make room for dying. The first story in this chapter has described the shift from the possibilities of surgery and further treatment to rapid decline as the advancing disease continues.

### 6.3 *Part[y]ing*

In this penultimate story I describe Jane's acceptance of her situation. A stream of family and friends from near and far pay homage at her court; it is a time of partying and parting. But first there is the matter of draining the excess fluid from her abdomen as promised by the oncologist at the clinic visit. I email my sister the following day:

Here things are not quite so good. We went to the clinic and the results weren't back for the tamoxifen and we thought Jane would probably have to have some of the excess fluid, which has been accumulating over the last few weeks, drained off. Sure enough we were back at the [hospital] for 9am yesterday morning for an ultrasound and then in [the day unit] until 4.30 after the insertion of a drain and 2.6 litres being drained. Jane feels the better of it but still has a fairly swollen belly. So the treatment worked for a wee while but the tumour is back on the march and there's not much more the NHS can do apart from dealing with symptoms. But we're persevering with the herbal things and the sunny disposition although sometimes the sky gets a wee bit grey and there's some rain. (Personal email, day 262)

The long and tedious procedure takes all day but I turn it into a day out complete with a picnic basket of provisions. Jane is admitted to the day unit by a hyper-efficient clinical nurse specialist (I am so jealous) and then sent for an ultrasound for 'x to mark the spot'. For the actual insertion of the drain, I am in my element: a surgical procedure. Jane is curious and interested. I provide a continuous commentary of all that is being done; the staff stoically get on with their work. I try not to be irritating but feel I must protect Jane from all but the absolutely necessary. Once the tube is in place, drainage proceeds cautiously for fear of causing shock by removing too much fluid at once (Stephenson & Gilbert, 2002). There is turning from side to side, walking about and generally trying to get as much fluid out and into the drainage bag. Finally, the tube runs dry and we can go home. Jane makes no mention in her diary but does note "Mum's come through to stay for a couple of days – opportunity for a candid chat about options and prognosis" (Jane's diary, day 261). Two days later she writes "Long talk with Mum this morning really cathartic for us both. Walk in sunshine this afternoon, glad to be alive" (Jane's diary, day 263).

The relief from the ascites drainage is short-lived as Jane has now developed low back pain, or at least it has started to bother her more than previously. We decide she should start taking regular analgesics. I had done some online research about palliative care, as much to find out about current practice, and came across the idea of an analgesic pathway. This concept was introduced by the World Health Organisation (WHO, 1990, 2004) as an analgesic ladder with three steps or rungs of increasingly strong analgesic medication. Level one is non-opioid drugs such as ibuprofen and paracetamol which are widely available to the general public. The second stage introduces a mild opioid, codeine which is also available without prescription. Finally, level three introduces opiates which are only available on prescription and in various forms ranging from an oral linctus, through slow-release tablets to injections. The drugs at each stage all have potential side effects such as gastric irritation. Opiates especially can cause severe constipation and initially vomiting necessitating counter-measures such as laxatives and anti-emetics. Before Jane has time to develop any real side-effects of the regular analgesic regime, we visit the GP for a review. The doctor makes an entry in the online records system which can then be accessed by all members of the primary health care team:

Consultation: Advancing ovarian Ca. Increasing ascites. Last drained 6 days ago Increasing already Some low back pain partic [sic] at night. Partner and her believe it is muscular in nature. Keen to try diazepam. Taking regular paracetamol and ibuprofen for pain relief. Given oramorph PRN and

diazepam. Agree to referral to Marie Curie. (Primary health care record, day 267)

This is it, the shift to palliation, the boundary transition between life and death (Froggatt, 1997). The GP does not prevaricate about the analgesia; Jane needs the strong stuff. I am relieved but know this news for what it is, the slow walk towards death within the next few months, hopefully not weeks. Referral to the community nurses and the palliative care service provided by Marie Curie, are mentioned as necessary next steps. We express our gratitude and acceptance of such support. Unsurprisingly although the morphine provides excellent pain relief, it also makes Jane very sick, a symptom that is to be a major feature of her remaining months. I email my sister following the visit to the GP:

Here things are not great as her majesty is somewhat indisposed with back pain and today has been taking the order of the barf. We're not sure if this is because of pressure on the stomach or a change in analgesics (morphine's lovely stuff but it can sometimes be barfy). Anyway I'm sure a good night's sleep and a quiet day will be restorative. We had hoped to go up to Abriachan tomorrow to collect plants but I'm drawing the line at buckets in the car. Her majesty will probably also be needing drained again early next week so nothing but fun for us. Please try not to worry about us, we're fine and it's all ok. (Personal email, day 268)

It is much easier for me to make a joke of the situation while being open and honest. Part of my coping mechanism is resorting to black or gallows humour, a throwback to when I worked in A & E. While this may seem inappropriate, it has been suggested it is a way of moving forward, from the horrific accident victim to the next patient (Watson, 2011). A systematic review of the use of humour by nurses found it a poorly researched area and suggested nurses should be circumspect in its use but aware of its value to release tension (McCreaddie & Wiggins, 2008). More positively, Smyth (2011) believes laughter has a place in palliative care. While I write with euphemistic humour, Jane takes a more direct approach when writing to her scientific cousin:

You may have gathered the news on the health front is not great. There's still a chance of a couple of drug trials but basically the forward plan is to 'keep me comfortable' for as long as possible. This includes day hospitalisation to insert a tube to drain off some of the fluid that gathers in my belly from time to time, which is a bit unpleasant but not as ghastly as it might sound. Otherwise we are just staying calm. Mum came through for a couple of days last week which was lovely, and a good opportunity for a long heart-to-heart. Life is too short to leave things unsaid! (Personal email, day 267)

Our humour and fortitude are severely tested at the weekend as the ascites has gathered again causing pain and pressure:

There was an awful, awful weekend when I thought she was going to burst. She was in considerable discomfort with it and she was very nauseated. The real problem was that the day unit only operates Monday to Friday so she couldn't go to have the ascites drained out with those hours. I was quite frustrated because when we'd gone for the initial drain they'd talked about how there was a new permanent drain. So I said well, can't we just do that then instead of keep putting Jane through this. But there's a protocol and there's a big cost implication because the drainage bottles cost £40 so special permission had to be granted. So we had this dreadful weekend where she just had swollen right up massively, was very nauseated and in a lot of pain until we eventually got to the Monday and she could go in to have it drained. (Interview 8, 15 October 2013)

This account gives some sense of the grim reality of advanced ovarian cancer 'an awful, awful weekend' and my frustration at the apparent vagaries of the health service 'special permission had to be granted'. It is hard to watch the pain and intolerable discomfort of the ascites whilst feeling powerless to do anything. Perhaps more effort should have been made for Jane to be admitted to hospital where, even at the weekend, the drainage procedure could have been performed. However, she is seen by various community doctors none of whom propose hospitalisation as an option; this was after all, a palliative situation. By Monday almost ten litres of ascites has accumulated; this was the great drainage. Three days later Jane notes the beneficial effect "Had sticky rice and smoked cod for tea and I was really hungry" (Jane's diary, day 276). During the admission for the paracentesis, Jane is told that the result of the oestrogen receptor test indicated Tamoxifen (a hormone antagonist) might be beneficial. The potential efficacy of hormone therapies that disrupt ovarian tumour growth has been known for many years (Hatch et al, 1991) and more precise therapies are becoming available (Smyth et al, 2007). For Jane, treatment is started but "It was explained that Tamoxifen is licensed for breast carcinoma but not for ovarian carcinoma although some patients do benefit. In addition plans are being put in place to have a PleurX catheter inserted in order to facilitate future drainages." (Hospital record, day 273).

The referral by the GP to the palliative care services has initiated visits from two important services, Marie Curie (MC) and the community (district) nurses. The week after the great drainage, the MC nurse visited for the first time. We have an open and frank discussion with her about what we know and understood of Jane's condition and prospects. Jane wants to die at

home but realises that as her condition deteriorates this might not be practicable. A few days later the district nurse arrives with a student nurse in tow:

The district nurse came for the initial visit to ascertain the lie of the land. Jane was on her couch in the window and [the district nurse] proceeded to say a little bit about what she could do and what might need to happen. We knew exactly what was going on, Jane was going to die, that wasn't going to be too long, she might need some additional care but Jane wanted to stay at home. So [the district nurse] kind of looked about and said well yes that would be fine but of course we'd need to bring in a hospital bed. At this point I looked at Jane and thought I'd better get the bucket and she was then very sick which startled both the district nurse and the student nurse. It wasn't entirely unexpected but I knew it was because Jane was really wound up about the prospect of bringing a hospital bed into our small flat and all of the upheaval that that would cause and the impact that that would have on us and not least our cats. (Interview 8, 15 October 2013)

Dying was hard enough but the prospect of it being somewhere strange, not at home (unhomelike) in her own bed, is just too much for Jane to bear. Her visceral reaction startles those present but the message seems clear. Jane is finding it difficult to press for what she wants as her strength wanes. However, the district nurse arranges for a ripple mattress to be delivered for Jane's side of the bed. Froggatt (1997) argues in her analysis of hospice settings and structures as rites of passage, the journey from life to death, that entry into hospice care marks the transition from the secular world. This is the separation from normal life (the life as known) until reincorporation after death through funerary rituals. When hospice and palliative care are provided in the person's own home, that place becomes sacred. There are rights and rituals to be respected. A ritual for us is asking people to remove their shoes on entry to the flat, although I am too scared to ask visiting doctors. At a deeper level, I wonder if Jane's reaction to the prospect of a hospital bed is because she has recently entered a liminal or threshold state and wants to assert her right to die in her own bed, a recent acquisition. The bed has its own sacred qualities, handmade for us in walnut, a wood associated with healing and inner peace.

Jane continues discussions with her family "Talked to [sisters and mother] about lack of any funeral. All ok I think" (Jane's diary, day 278). Then two days later "I have written 'what you mean to me' emails to [sisters and cousins]. Had long talk with [cousins]. Feeling very very warm and loved." (Jane's diary, day 280). She also has a discussion with my sister "Didn't just talk about sickness and death but mostly did. Now it's all said we can all get on with the rather splendid business of living" (Jane's diary, day 283). Reflecting on this time now, it seems as if the

great draining both energised Jane and galvanised her into addressing family matters. She realised her life was diminishing but wanted to act on her feelings while she could. The relief of the great drainage is more temporary than we hoped as I tell my sister:

Her majesty has turned into Mme Creosote<sup>52</sup> and is fine as long as she doesn't have a wafer thin mint or any other solid food. But she is doing very well on full strength Ovaltine and special leek & potato soup with extra milk protein. We have to persevere until next Monday when they will do the permanent drain which will makes things a lot easier. So that's some good news. (Personal email, day 281)

The management of malignant<sup>53</sup> ascites has exercised the health profession for many years (Stephenson & Gilbert, 2002). The most common cause of fluid accumulating in the abdomen is due to cirrhosis but 20% of ascites are non-hepatic in origin (Stanojevic et al, 2004). Consequently until recently the evidence for appropriate treatment protocols was based on best practice in the context of liver disease and not malignancy despite the very different pathology (Stephenson & Gilbert, 2002). Essentially there are two ways in which accumulated excess fluid might be removed from the abdomen, either by drug therapy or by manual drainage. There was sufficient concern within the gynaecological oncology community for Macdonald et al (2006) to conduct a survey of clinical staff on the management of ascites in ovarian cancer. They found considerable variation between both clinical speciality – gynaecologists tended to use more interventions than physicians (oncologists and palliative consultants) – and between hospital settings, where diuretics were preferred to paracentesis in palliative centres. The limited efficacy of diuretics was noted by Mercandante et al (2008) who favoured a permanent peritoneal catheter to facilitate home drainage and reduce the symptom burden. However, the authors also noted that at the time no catheter designed for peritoneal use existed and their solution was therefore unlicensed. This combined with the lack of a standardised protocol for the palliative treatment of malignant ascites prompted Fleming et al (2009) to conduct a systematic review and recommend a permanent solution for repeated paracenteses.

The symptoms experienced by women with ovarian malignant ascites are distressing and troublesome. In addition to the tense abdominal pressure and distension, patients may also experience nausea, vomiting, early satiety, shortness of breath, swollen legs and reduced mobility

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52 This is a reference to the revolting scene in the Monty Python film, 'The Meaning of Life', when the morbidly obese and glutinous character Monsieur Creosote explodes (see Michael, 2013 for gory details).

53 The accumulation of fluid in the abdominal cavity as a result of neoplastic disease (Parsons, 1996).

(Tapping et al, 2012). Unfortunately these symptoms also tend to occur in the last weeks and months of life making repeated hospital attendance and admissions an unwanted burden at a difficult time for both the woman and her family. Having established, as outlined in the studies cited above, the preference and efficacy of drainage over drug therapy, the need for a more permanent solution was proposed which involves the insertion of an in-dwelling plastic catheter into the abdominal cavity. The internal tubing is held in place by a fifteen centimetre section being tunnelled subcutaneously and then sutured in place. Vacuum drainage bottles are then used to suck the fluid out by negative pressure. Drainage can be done daily on the basis that a little more often is preferable to the accumulation of many litres of ascitic fluid (Tapping et al, 2012). This PleurX peritoneal drainage system has now been approved by NICE for use in England (Kmietowicz, 2012).

Other research has proposed novel drug therapies that exploit particular mechanisms in the pathophysiology of malignant ascites. For example in the healthy body there is a natural balance in the vascular environment for the maintenance of blood cells through angiogenesis, the process for the development of new blood vessels. However, in the diseased body this balance becomes disrupted as the formation of new blood vessels is demanded by the growing tumour. Vascular endothelial growth factor (VEGF) has been identified as being essential for both tumour growth and the formation of ascites but it can be inhibited by the antibodies bevacizumab or catumaxomab (Eskander & Tewari, 2012). It is hoped that further advances in the understanding of the pathophysiology of ovarian cancer ascites and the molecular features of the disease will lead to more precise and effective treatments in the near future (Kipps et al, 2013). This optimism is tempered by the need for larger scale trials to determine both the efficacy of symptom relief and overall survival (Smolle et al, 2014).

Finally the day arrives for the insertion of the permanent drain. Jane attends the day unit and hopes to be home by evening. However, her blood biochemistry has become disrupted, another common effect of malignant ascites. As the ascitic fluid has a high protein concentration the direction of fluid travel across the peritoneal membrane is switched so that fluid flows into as opposed to out of, the abdomen (Kipps et al, 2013). This haemodynamic mechanism was first described by the British physiologist Ernest Starling (1896), a historical point that would have fascinated Jane. The lead oncologist is on holiday and the duty registrar decides to actively treat the chemical imbalance. Had Jane's high potassium level not been treated she could have

developed an arrhythmia causing her heart to stop beating. It would have been a quick and relatively painless way to die but she was not quite ready to leave (Copp, 1998).

The actual procedure for the insertion of the PleurX drain is recorded in both the discharge letter and the radiology report as being ‘uneventful’. However, our experience does not concur with these observations. I was allowed to go into the x-ray theatre and stay with Jane throughout. I play my former-ward-sister-at-the-hospital card, and provided I change into scrubs, the staff are most accommodating. As Jane is pushed in a wheelchair into the theatre suite, the staff nurse acknowledges her as ‘Mrs Plenderleith’. I immediately react by saying she is not ‘Mrs’ but ‘doctor’. This proves to be a welcome distraction for Jane as she is then able to explain she is not a medical doctor and outlines her PhD. When I return from the changing room, she is deep in conversation with the staff nurse on the finer points of the philosophy of Moses Mendelssohn<sup>54</sup>, an indication that 18th century German philosophy is never far from her mind. With some difficulty she manages to get onto the rigid, narrow x-ray theatre table and is asked to ‘lie back’. I intervene explaining she cannot lie flat, if she does she will vomit. Jane paled, the staff insisted and she throws up, causing commotion and embarrassment. She then has to stay in hospital until her blood biochemistry stabilises. She ignores the unpleasantness and writes instead “Spent night in [hospital] – they were helping me to feel better” (Jane’s pink diary, day 286).

As the PleurX drain is a new device, the manufacturer’s representative had come to provide training for the hospital staff. I am allowed to participate in the training so I can manage the drain once Jane is home. The district nurse visits the day after Jane’s discharge to inspect the drain and see it in operation as it is also new in the community:

There was quite a lot of blood coming off that I’m a bit concerned about. So she did a full blood count and the results went to the hospital and they saw that [Jane’s] haemoglobin had fallen to 77<sup>55</sup>. So she was re-admitted and transfused with three units of packed cells but why was she bleeding? I felt sure that they had dislodged some tumour from the inside of her abdominal wall when the trocar was used to make to a hole. (Interview 9, 22 October 2013)

Repeated abdominal paracentesis has the potential risk of both bleeding and infection (Fleming, 2009) one of the cited advantages of the PleurX system is that it reduces these risks (Tapping, 2012). My recollection in the interview extract does offer an explanation and also alludes to my

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<sup>54</sup> Father of the composer Felix and a German philosopher and to whom the founding of the Jewish enlightenment is sometimes attributed (Arkush, 2007).

<sup>55</sup> The normal range is 115–165 g/L



frustration when I noticed the drained fluid was heavily blood-stained. When I ask how we are to dispose of the drainage bottles I am told to empty them down the toilet and then put the bottle in the general waste. It seems there is no provision in the community for the environmentally conscious disposal of medical waste nor any great concern either. We comment to each other how quickly we have pushed aside long held beliefs and behaviours in the wake of Jane's declining health and increasing care needs. Jane makes no comment on this episode and instead writes about the food treats she is now able to enjoy. First, "Had to stay in. [Veronica] came back from Waitrose with choice food for palliative care – smoked salmon bruschetta and chocolate ice cream" (Jane's diary, day 289) and then "avocado splosh and a puzzle book to keep me busy. Fantastic view of the Edinburgh skyline from my window" (Jane's diary, day 290). The hospital discharge letter summarises events:

Jane was admitted as an emergency from home with increasing SOB [shortness of breath] and lethargy, bloods taken by your district nursing team confirmed that Jane was anaemic. She was transfused 3 units of RBC [red blood cells], commenced on tranexamic acid and her high potassium was treated with insulin/dextrose during this admission. Jane had a CT scan which showed no active bleeding and the pleurX catheter in a satisfactory position, it did however confirm disease progression. [The oncologist] after discussion with Jane have [sic] agreed that no further bloods should be checked, the aim of treatment being symptom control with community palliative care input. (Hospital discharge letter, day 293).

When the lead oncologist comes to review Jane on Monday morning, she asks him a straight question 'how much longer do you think I have?' and receives a straight answer 'a number of weeks'. Her version in a blog post omits this temporal information and gives a different interpretation:

Meanwhile, I've been a bit poorly. Without going into too much detail, the fluid gathering in my abdomen was making eating and drinking increasingly problematic. Draining the fluid while maintaining some kind of blood chemistry balance proved something of a challenge for the NHS staff at the [hospital] (for whom I have nothing but thanks and praise). I now have a permanent drain fitted which makes 'little and often' drainage possible. [The oncologist] came back from leave on Monday and decreed, with which [we] wholeheartedly concur, that no further heroic chemical balance exploits should be attempted, that I should be allowed to come home to my own comforts. District nurses and Marie Curie are there to help when we need them, and [Veronica is] able to drain as much or as little as we think appropriate. Even more to the point, it keeps me hungry, or

peckish at least! It's official, I can eat whatever I like. Sometimes my requests are reasonably adult (I want sushi), others amusingly childish (chips, cola, chocolate ice cream). I can spend much of the afternoon deciding whether I'd rather have my hot smoked salmon peppered or honeyed, and basil or chives in my avocado salsa (with chips of course). Curiously enough, I am having a rather lovely time :) (Blog post, 'Catching up', day 291)

Jane's demeanour following the ascitic draining and blood replenishment give the impression of catharsis; she is energised, almost renewed. By this time her life is reduced to minuscule, intense and exquisite moments that she relishes and savours. These range from the food she eats through excursions out, to the many visitors who journey to see her from near and far. In this invigorated state Jane writes about her impending demise:

An archaeologist on Orkney once explained to me that nothing helps anthropologists to understand a historical civilisation and society better than its practices and traditions for dealing with its dead. Burial places, rites and rituals, accompanying objects, carvings, gravestones, mummification, ceremonial pyres, cremation, urns and ash disposal – all have something to say about how societies respect their dead. Mostly they are also expressing some kind of appreciation for the life lived. But more importantly, these funerary rites generally reflect the way a civilisation thinks its dead should be prepared and furnished for some kind of transference to another world.

Many years ago, long before my cancer diagnosis, we made the decision, and the arrangements, to donate our bodies to medical science. All usable organs were to be transferred to appropriate donors, and the rest sent to the Anatomy Department of [a university]. They won't want my organs now, but apparently there is still interest in receiving the body. So there isn't going to be any funeral for me – no body, no coffin, no service, no cremation.

I was brought up as a Christian in the Church of Scotland in Glasgow. I've always been grateful for my Sunday School grounding in the stories and imagery of the Bible, which proved essential background knowledge for an appreciation of the literature and culture of the Western Judaeo-Christian tradition (culminating, I suppose, in the subject-matter of my PhD thesis). I was a regular and enthusiastic church-attender from my teenage years. But I was finding it increasingly difficult to accept – and believe – the central tenets of the Christian faith.

When I went north to work in Inverness, I became distanced from the church, in more ways than one. I felt able to acknowledge that my 'doubts' were not a failing on my part, for which I required to do social penance. My parents taught me, by word and example and by the entirely comfortable

and secure context of our upbringing, how to determine right from wrong for myself, to be kind, and fair, and understand the meaning of justice. Not being a Christian does not mean not being a good person. Not being a Christian does not mean I have not been profoundly touched by the thoughts and prayers of so many people – some known and very close to me, some complete strangers – who have been remembering me in their communion with their God these past months. It's odd that I find myself describing my position in a series of double negatives, of course. Atheism is an unpleasant word; it implies an antagonism I do not feel. If I do require a concept to describe my world-view, perhaps humanism comes closest.

Whatever you call it, it's a strong and powerful position to be in. I am reconciled to my lot, I do not rail against any external forces which have dealt me any cruel blows, I do not expect any miracles. I cannot in any conscience countenance a Christian funeral for myself. Nor even a humanist one. I do understand that funerals are intended for the mourners rather than the deceased. There's something I find entirely inappropriate about someone who never – or hardly – knew me talking about the life I lived while those I love have to sit and listen. I feel very strongly that anyone who would like to 'pay their respects' can do so – and are indeed doing so – while I am still here and able to enjoy their company and comfort. Is that terribly selfish of me? There are other ways of marking my passing than with a coffin and a crematorium. Have a party. Drink Loire fizz and fine whiskies. Eat cake and chocolate ice cream. Tell terrible jokes. Play the piano, sing very loud and out of tune. Have a laugh. It's your funerary right. (Blog post, 'Funerary rites', day 297)

It could be argued that by being at the centre of her own drama, Jane is maintaining her self-esteem and reducing any anxiety she has of her approaching death. This accords with the view that "In order to keep the anxiety-buffer provided by self-esteem, one must continually reaffirm one's value and one's faith in the absolute validity of one's world view." (Greenberg et al, 1986: 199). In recounting fond memories and reminiscing on her former healthy self, Jane is able to maintain her strong sense of self and the ability to cope with her situation. It has been suggested that an illusory process of looking at known facts in a particular way enables cognitive adaptation to occur (Taylor, 1983). By thinking of healthier times, Jane is able to pretend she is well and can ignore her terminal decline. However, I believe 'Funerary rites' illustrates, she was under no illusion nor particularly anxious but she would have liked to be at the party.

## 6.4 Dying

This story concludes the dance and recounts Jane's final month. From my earlier research of current palliative care guidelines, I have been privately preparing what needs to be done. The

district nurse has brought an ‘anticipatory drugs pack’ complete with needles, syringes and a sharps disposal box. I put them in the cocktail cupboard. The purpose of the anticipatory prescribing is for those who are dying at home to have easy access to medication without unnecessary delay. When the time comes, I am allowed to administer any of the drugs subcutaneously. The table summarises the type and purpose of each (NHS Lothian, 2010):

Type	Drug Dose & Frequency	Purpose
Analgesic	Morphine sulphate injection 2mg hourly	Pain or breathlessness
Sedative	Midazolam injection 2mg - 5mg hourly	Anxiety / distress
Anti-secretory	Hyoscine butylbromide injection (Buscopan) 20mg hourly	Respiratory secretions
Antiemetic	Levomepromazine injection 2.5mg 12 hourly	Nausea

**Table 6.1 Anticipatory Drugs**

The metastatic tumours in Jane’s abdomen are now pressing on her gastrointestinal tract to such an extent that a complicated cocktail of drugs is prescribed in an attempt to manage the worst of the nausea and vomiting. Unfortunately but perhaps inevitably these oral drugs are not well absorbed and no longer have much effect. When the Marie Curie nurse comes for her next visit she suggests it is time for a syringe driver to continuously administer a different anti-emetic. Within hours of the decision, the district nurse arrives with a large plastic crate and sets up the syringe driver, a portable infusion pump that will last 24 hours. Ironically, although Jane now feels more confident that she will not vomit if she goes out, she has to carry this unwieldy contraption. However, she quickly adapts choosing a cotton bag for outings and a plastic supermarket bag for protection in the shower. All things considered, the pump boosts rather than reduces her independence. It makes a family visit to Glasgow the following day possible, even going out for lunch. Jane’s is a ‘paediatric’ soup and pudding. We then attend a fund-raising event at her cousin’s where she holds court from an armchair. It is a fortuitous opportunity for many family members who will not get to see her again. Friends continue to visit:

It’s so lovely that people’s first reaction is to come and see me. I really do feel completely surrounded by love and support. I’m calm about what’s ahead, but for now, I’m thoroughly enjoying each moment of my life. Through all this, of course, [Veronica] remains an incredible tower of strength. She never stops looking out for me, listening for every breath, anything unusual, always aware of where I am, what I’m doing, what I’m eating and drinking, sorting drugs, drains and dressings. Even when she’s sleeping she’s still got half an ear listening for me. She’s a tiny bit marvellous, to put it mildly.

(Blog post 'Friends and Family', day 307)

I was not sure if I should include that extract about my performance as I find it embarrassing. At the time I know I wanted to be recognised as essential to Jane's well-being but now I also recognise that my Amazonian presence may have made it difficult for others to be involved in Jane's care.

Following the visit of a former work colleague, whom she had not seen for many years, Jane noted in her diary:

[Colleague] came for coffee this morning. Like it's been no time at all – instead of years – since I last saw her. Big hugs. And 'hello beautiful' is a nice way to be greeted. (Jane's pink diary, day 311).

Jane's appearance has changed considerably since the onset of her illness. After the chemotherapy-induced alopecia, her hair has regrown into a wiry grey mop which she is no longer interested in colouring for a more youthful look. Her face is thin and gaunt, her abdomen enormous and she walks with a slow waddle. She seems to have aged thirty years in a few weeks. For someone to say with sincerity that she is beautiful is powerful and compassionate. Much as she loves to go out to parks and gardens she is now too weak and immobile to walk any distance. I hire a wheelchair, a heavy cumbersome beast but it means I can really push her around. She takes her debility in her stride and writes "pushed around Botanics this afternoon – cold but lovely to be out in the fresh air and smell the blossom. Then we had an ice cream!" (Jane's diary, day 320). It is not many days after the start of the anti-emetic syringe driver before I have to give her an additional 'breakthrough' dose. At first it is just the odd one, not every day but the frequency gradually creeps up. A fortnight after the arrival of the syringe driver, Jane needs two or three extra doses from late evening and through the night.

I record every drug and dose I give in both the community nursing record and a spreadsheet. I do not really believe anyone is going to either question or challenge what I am doing; these are legitimately prescribed drugs. Yet I worry, wanting to give Jane the best care, reproaching myself for not realising she was ill until it was far too late. The district nurse visits each morning to refill the syringe driver but then has to hurry away for her next visit. I want her to say we are doing okay, that everything is going to be all right. We muddle on, propping each other up through grey moments and occasional tears. Jane manage small achievements "Finished Fair Isle tea-cosy! (Also, it's 4 weeks today since 'how long' conversation with [the oncologist])" (Jane's diary, day 321).

Managing Jane's diet is also especially challenging as food, both in preparation and eating, has been one of our great shared loves:

Interviewer: How did Jane deal with the kind of limited capacity she had to take in food?

VA: I suppose the thing that was difficult was that her senses, particularly smell and hearing, were enhanced by the morphine.<sup>56</sup> I had to be really careful with food smells of what I was eating or even indeed cat food smells because she would really notice them and they weren't particularly pleasant for her. She was taking immense and intense pleasure in very small things so a frozen strawberry which she could suck or there were various ice creams. Ultimately it was just down to lemon sorbet.

Interviewer: But there were still things that she could actually enjoy although in very small quantities?

VA: Yes, the amuse bouche had become almost microscopic, it was little intense tastes. Initially her preference was for quite savoury things. I found in one of the palliative care guidelines, it was about tempting people. Mostly they're about using really sweet things but what she wanted was something quite savoury. Mashed up egg with avocado which she found very tasty. But then, as things deteriorated eating-wise she didn't mind if things were sweeter like ice creams and sorbets but not sickly sweet. (Interview 11, 5 November 2013)

The issue of where to die remains unresolved; the spectre of the hospital bed in the living room still looms. The alternative is the hospice when the time comes. On a routine visit, the district nurse suggests Jane might benefit from a review by the palliative team of her drug therapy to try and reduce the nausea and vomiting. The experience is a defining moment for Jane:

We have had many conversations over the past months about my final days and how best to deal with what might be ahead. I hope that will be understood as pragmatic forward planning rather than some maudlin fascination with my end. We've had many conversations about lots of other things as well. Anyway, plan A was for me to be looked after here at home. However, we were somewhat disturbed by an early conversation with the district nurse team which implied that this option was only open if we were able to accommodate a hospital bed and a commode. That was just too much to contemplate in our lovely wee flat. I couldn't really see myself lying in the window propped up in my hospital bed, waving at the passengers on the upstairs deck of each passing bus, with a commode in front of the

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56 This proved to be an urban myth and I am not sure where the idea originated. However, it was the chemotherapy that caused Jane's heightened olfactory awareness and altered sense of taste (Bernhardson et al, 2009).

fireplace.

So we came round to thinking about plan B, which was to spend my last few days (I felt, and still feel, quite strongly that I will know when this time comes, and it's not any time very soon) in the local hospice which is just ten minutes drive up the road. We went for a wee recce last week, taking advantage of the visit for each of us to have a very pleasant relaxing massage. The grounds are lovely, especially at the moment when the cherry blossom is in full bloom. The atmosphere was calm and relaxing.

I've been a bit bothered by digestive problems over the past few weeks. It's characteristic of the progression of my disease, things pressing on internal organs, and on the nervous system that generally helps things to work. I was feeling pretty awful yesterday morning when the district nurse came for her usual daily visit, and she suggested that I should admit myself to the hospice to try to get my drugs regime sorted. We concurred, got some things together, and arrived there late morning. We were shown into a room with a bed and a variety of chairs, and waited. We waited quite a long time. At about eight o'clock last night, my drugs were changed to an agreed new regime. I spent a reasonably comfortable night in the hospice. Without going into too much detail, I didn't throw up for the first time in what seems like weeks so that is a definite improvement.

However, in the course of the evening we absolutely resolved that I was getting out of the hospice today. One night was enough. The staff are kind, and well-meaning, and the hospice clearly plays a vital role in the care and support of a vast number of cancer sufferers and their families. But with the best will in the world the care is necessarily institutionalised, and dependent on staff availability rather than immediate patient needs. The nursing staff were not at all sure about letting me home, there was even talk of staying for a week. I don't have that many weeks left that I wanted to spend one there. The palliative consultant was entirely understanding and supportive of our wishes, and confident that we have the necessary wherewithal to put in place a care plan to look after me at home. Nevertheless, it did feel a little bit like a break-out, and is certainly a huge relief to be writing this from my throne by the window with my view of the hills. [Veronica] is ready and able to continue to provide entirely patient-centred care. She's there for me whenever I need whatever I want. For as long as it takes. We are back on Plan A. (Blog post 'Breaking out of the Hospice', day 323)

Following the overnight stay in the hospice Jane now has two syringe drivers, one in each arm; the new driver contains morphine and a sedative, in the other is the anti-emetic at a much higher dose. The parting advice from the palliative care consultant, when asked if there is anything else we could or should do for Jane's comfort, is 'you have plenty of drugs in the house,

so use them'. The hospice encounter highlights another aspect of Froggatt's (1998) analysis of hospice care: the sense of *communitas* exemplified by a lack of hierarchy. The palliative consultant is quick to respond to Jane's stated wishes. He phones the district nurse and dissolves her concerns regarding suitable beds for the dying and our ability to cope. Her role and attitude are framed within the secular structure of community care where patients can be subordinated to the views and opinions of the health care professionals. By insisting that a hospital bed would be required, she is asserting her authority and status over us. In crossing the limen, preparations need to be made to care for Jane in her last days. In the sacred setting of hospice care, the patient has equal status. Curiously, the hospice itself was not quite the sacred space that Froggatt (1998) describes. What Jane does not mention is the rigid routine operated by the nursing staff, a very secular structure. Taking pills is difficult for Jane and she is accustomed to having her evening medication at a particular time. When we ask for them, we are told that the staff have started the drug round 'at the other end' so she would get hers when they are ready.

Jane continues to note positive thoughts and experiences in her diary:

- Constant round of visitors & phone calls today. Exhausting but feel very loved. (day 324)
- [Veronica] pushed me around [the reservoir]. Sunshine, blue sky, warblers, primroses, bluebells, coconut-smelling gorse. (day 326)
- Went to Botanics. Loads more rhododendrons & azaleas coming into bloom, wheelchair is at optimum height for appreciating scent. (day 329)
- [My brother and partner] left, not saying goodbye, instead 'Skype you tomorrow'. [Youngest sister] wants to cherish last memories of me on the beach at St Andrews (day 330)
- [Younger sister] brought mum through this afternoon – no more visitors now. Not sorry. It's been lovely, and full of love, but I'm tired. Just me and [Veronica] now. (day 332)
- Dozed all day. Feel very calm and peaceful. (day, 333)
- There's nothing quite like a frozen strawberry for reviving a droughty mouth. (day 334)
- Wouldn't you just die without lemon sorbet (sorry). (day 337)



Friends and family offer to come and 'babysit' but I feel I cannot leave Jane with someone else. I know she just wants me to attend to everything but I do email my sister:

Just a wee update as I know you'll be wondering how we're doing – I was going to phone but I don't want to be a moaning minnie and mostly it's ok, just a teeny bit harder each day. Jane is getting weaker and very sleepy but manages to wake at regular intervals for lemon sorbet! The drivers seems to be alleviating the worst of her symptoms, the downside being the drowsiness. Now she's passed all her deadlines she's not making anymore!  
(Personal email, day 337)

Reading this now and my excuse for not phoning, it occurs to me that I did not phone because I could not speak of what I was experiencing. The complexity of researching suffering is well understood by Frank which he describes with a precise profundity that resonates with me:

Suffering involves experiencing yourself on the other side of life as it should be, and no thing, no material resource, can bridge that separation. Suffering is what lies beyond such help. Suffering is the unspeakable, as opposed to what can be spoken; it is what remains concealed, impossible to reveal; it remains in darkness, eluding illumination; and it is dread, beyond what is tangible even if hurtful. Suffering is loss, present or anticipated, and loss is another instance of no thing, an absence. (Frank, 2001: 355)

The quotation ends with the statement that suffering is expressed in myth as the wound that cannot be healed, which I suggest is a reference to that introduced in Section 5.2 as the legendary wound of Amfortas in Parsifal. However, Frank does not reference Jung who recognised that the personal experience of the analyst may make them a wounded healer in relation to their patient (Samuels et al, 1986). While I have no personal experience of cancer, nor indeed dying, perhaps I was wounded by my previous nursing experience particularly in caring for women with advanced cancer.

The following day (Thursday) Jane makes her last diary entry (day 338) but it is too personal to share here. Friday starts like most other days of the past few weeks. With great effort Jane manages to have a shower, the two syringe drivers balanced precariously on the end of the bath. Eventually she is dressed, ensconced on the couch, managing a little sorbet. Her breathing is stertorous, wherever I am in the flat, I can hear the heavy effort. In the afternoon she asks for some breakthrough morphine and then to go through to bed; she can no longer get comfortable on the couch. I help her to undress, she hugs me and says now she just wants to stay in bed. In her naked state she is, as Turner (1969: 95) describes, a 'liminal entity' without possessions to

demonstrate status, property, insignia, or secular clothing. This act completes the threshold crossing to the innermost sanctum.

I worry about turning her in a king size bed and pressure sores and all the other basic care drills in my head. The community nursing team produce a glide sheet<sup>57</sup> so I can turn her from side to side. I find that if I stand on top of the bed, I can pull Jane up the bed so she can still have a blurry view of the tree outside the window.

Over the weekend a succession of different community nurses visit to refill the syringe drivers. Jane waits peacefully. Her mother and younger sister want to visit again on the Sunday and although Jane has decreed no more visitors, we can hardly refuse. The scientific cousin wants to visit but cannot get to Edinburgh until Monday. Off stage her mother and I communicate about the realities she might face but she is determined to come and Jane wants to see her. Drawing on evidence from her study of patients facing death, Copp (1998) proposes that the dying experience an awareness of a separation between the body and the person (self). While acknowledging that her theory is largely hypothetical, she suggests that some may experience a sense of the body being ready for death when the person is not. I have a sense, that Jane is waiting, hanging on, for the visit of her young cousin. There is a determination in her despite her clearly dying state. Yet, I have my doubts she will last but I try to remain optimistic; that evening I email my sister:

Here it's been another day on the downhill bobsleigh with HRH getting more happy mixture in her pump this morning and then being very drowsy all day. However, [the scientific cousin] came up for a visit which we didn't think she would manage in time but Jane was really pleased that she did. Yesterday [Jane's mother and younger sister] came through which wasn't easy but everyone was glad they did. It's particularly hard when people come to say goodbye although [the scientific cousin], who's just turned 21, was very adult, kind and strong. Anyway, when I've finished my wee dram, even though it's a school night, I'd better go to bed as you never know when you're going to need to spring into coherent action around here. (Personal email, day 342).

Now, as I write it is more than three years since Jane became ill and although my memory of Jane's final hours still seem clear, it is not as vivid as it was for the interviews. I used the email quotation as a prompt in the storyboard to be asked about Jane's death in the last interview. However, the interviewer's interest centred on the last visits of Jane's family. We both became

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<sup>57</sup> I was unaware of such innovations as they did not exist in the 1980s.

upset and the interview was paused. After I explained that I had not been able to describe the end, we restarted:

Interviewer: Can you say a bit about how that went, after [the scientific cousin] had visited.

VA: She left mid-afternoon and I continued to check [Jane] was okay and that she was comfortable. She was mostly just breathing heavily and drifting in and out of sleep. I didn't feel needed to stay at her side, she knew I could see her from the living room and that I could hear the slightest thing. So I spent a quiet evening, lots of people kept sending texts, her sisters, close friends and I had various little reassuring messages to send that she was comfortable and it was okay.

Eventually I went to bed and I was up a couple of times during the night. Between three and four she was quite nauseated again I was giving her hyoscine which was making her mouth dry. Each time when I got up, I turned her to the other side and so about four I'd got back into bed and fell asleep. I remember waking up very suddenly, shortly after seven, and looked at her and she was dead. I think I possibly woke up with her last breath. I didn't want to watch her die, to keep wondering if that was the last breath. I knew that I would wake with the slightest thing. (Interview 11, 5 November 2013)

Finally, 343 days after the train journey when I first noticed that there might be something seriously wrong with Jane, she has died from advanced ovarian cancer. The final month was as she wanted, at home with me and our two cats. Family and friends were in close contact, visiting as she withdrew from public life. She directed the dance to the end, clear in her desires and wishes.

## 6.5 Summary

In Part Two the narrative account of the Illness Period has been presented with reference to relevant literature using a style that draws on that suggested by *embodied relational understanding* (Todres & Galvin, 2008). In the three chapters and nine stories of the Dance to Death there are two turning points, the first in Section 5.3 when Jane visits the herbalist and takes active responsibility for her situation. The second comes in Section 6.2 following the laparoscopy when active treatment of her disease gives way to palliation. There is an apparent shift in the narrative as the medical voice from the health records fades away, replaced by Jane's enthusiasm for the exquisite. Part Three now revisits aspects of the Illness Period to consider the evidence of aesthetic experience and binary synthesis as a return enhanced.

## Part Three: The Aesthetic Experience of Dying

The final part of the thesis addresses the three remaining research questions. It reviews the Dance to Death from Part Two to make the connection between what was witnessed and my interpretation of Jane's personal philosophy. Two particular aspects are explored: the features of aesthetic experience as a facet of living while dying, and the return enhanced as the interplay between apparently opposite concepts. Chapter seven contrasts the types of stories told in Part Two with other interpretations and renditions of illness narratives. The relationship between the aesthetic features identified and the relevance of Schiller's *Aesthetic Letters* and Goethe's *Urphänomenon* are discussed in chapter eight. Finally, chapter nine reviews and appraises the study as a whole, first by reviewing the methodology, then summarising evidence in support of the research questions and concluding with a discussion of the findings of the research.

## 7 Narrating Illness

### 7.1 Introduction

To understand what happened to Jane and to us as life partners, it seemed necessary to tell many stories from the Illness Period. The extracts used range from minimalist, one word headings to more explicit accounts of particular events and episodes. In an earlier draft I wrote that I wanted the reader to have a strong sense of the visceral reality of advanced cancer and of the poisonous treatment. However, in comparison with others who have written of their personal experience, particularly of ovarian cancer (Rose, 1995; Gubar, 2012), this version is actually quite mild. My audience in this thesis is the academic community; Jane's blog post readers were her fans: the social network of family, friends and former colleagues solicitous for news of her progress. Our dissimilar purposes require different styles. Mine, particularly with regard to Part Two, attempts an embodied interpretation of a shared experience which is in parts uncomfortable. Jane's style is witty, humorous with dashes of dark truths edged with light relief. In constructing and analysing the narrative account I had wanted to create a "pedagogy of suffering" (Frank, 2013: 145) as something from which society could learn. Yet she rarely wrote about her illness and suffering, instead her narrative is like Frank's account of Miss Tod as "simply being" (Frank, 2013: 211). What finally emerges is a more contemplative account. In this chapter I re-explore some of the stories from Part Two and compare them first with reference to Frank's typology of illness narratives (Frank, 2013). Secondly, these stories are contrasted with other similar illness writings.

## 7.2 *A Contemplative Narrative of Suffering*

In the study corpus only five of Jane's thirty four blog posts are specifically about her illness. There are references to it in others but as an aside and not as the focus. The story she really tells in the Illness Period is not one of suffering and disruption but of a life well lived. However, before I elaborate on this point, I want to outline my conceptualisation of suffering. Previously I believed suffering was an indication of failure on the part of carers, whether professional or lay. If a sick person was suffering then in a simplistic sense, someone had not cared for them correctly. Insufficient pain relief had been given or pillows had not been plumped correctly: the doctrine of my nurse training. In reviewing the literature, I was drawn to Buddhist interpretations of suffering. While I can embrace many aspects of Buddhist philosophy, I come unstuck with the core precept that we are the cause of our own suffering. It seems to imply that suffering must then be our fault; an existential blame game. This is a misunderstanding of both Buddhist teaching and the meaning of suffering (Morgan, 2005). In Buddhist terms, people are spiritually asleep. To become compassionate and fully integrated to the nature of reality, they must awake from "the delusions which cause attachment and thus suffering" (Harvey, 2013: 2). Existential suffering results from "the feelings of alienation, frustration, and despair that inevitably arise when we confront the fact of our own impermanence" (Siderits, 2011: 303).

Conventionally, suffering is understood in terms of pain and its negation, and to be unwell. Yet the medical model can be impotent to suffering that is not directly connected to a particular illness or disease (Frank, 2001). In this indefinable sense "To suffer is to lose your grip. Suffering is expressed in myth as the wound that does not kill but cannot be healed" (Frank, 2001: 355). This suggests a sense of permanence as a scar from an experience that has been endured and a pedagogical interpretation of suffering as "what the ill have to teach society" (Frank, 2013: 145). It was in this sense that I first explored the narrative accounts of Jane's illness as she endured it and as I had witnessed it. However, a more contemplative approach goes beyond clinical reasoning to look at the moral aspects of events for their inherent goodness (Mattingly, 1998), to appreciate the process of the return enhanced. By returning to the difficult experience of Jane's illness and her dying, my understanding has been enhanced by dwelling in that place with the coherent integration and not active separation (Galvin & Todres, 2007) of clinical reasoning with the practice of the 'best good' (Mattingly, 1998: 291).

### 7.3 *Illness Stories*

If life can be well lived despite suffering ill health, “how will I find ways to avoid feeling that my life is diminished by illness and eventually dying?” (Frank, 2013: xvi). The term ‘bucket list’, popularised primarily through the 2007 film<sup>58</sup> of the same name, has become the “companion story” (Frank, 2010: 43) to guide those facing a diagnosis of life-limiting illness. This is the wish list of life experiences deemed most essential before premature death and foregrounds the quest for life to be undiminished by illness. Frank derived his concept of companion stories from two ideas. Firstly, stories are performative materials (Law, 2000) capable of shape-shifting in their retelling. The second aspect, that they are inherently evolutionary, was inspired by Donna Haraway’s manifesto on companion species. She argues that dogs are a typical companion species which has evolved from the wolf into the domestic friend to whom many are now “bonded in significant otherness” (Haraway, 2003: 16). The two essential features of companion stories are firstly that similar stories shape one another in a process of coevolution. Secondly, companion stories take care of each other through this shaping process (Frank, 2010). The phrase ‘bucket list’ is a derivation of the slang expression ‘to kick the bucket’. However, the bucket in this sense has its origins in the old French word for balance, meaning a yoke or beam, on which anything could be hung (SOED, 2007). Neither of these expressions are stories as such but they are signifiers of stories about death and dying. Telling a story about kicking the bucket could be an irreverent way of disclosing the death of an acquaintance. A bucket list story might tell of a young person who manages to pack many exciting experiences into a life foreshortened by cancer. As a type of story it would belong to the genre of epic, as ‘things to see/do/witness/taste before you die’.

For us, a bucket list is never mentioned, instead Jane notes “Last Thursday we achieved another tick on our ‘Things to do in Edinburgh’ list with a visit to the zoo.” (Blog post, A Day at the Zoo, day 137). The list is not discussed but exists in Jane’s head. She has a particular preference for ordering tasks as a checklist which is then awarded ticks in a manner reminiscent of a sticky star from a school teacher. In another blog post she lists various cultural events we have attended. Life is being lived at full tilt:

There’s no doubting our social life is much improved since we’ve been living in Edinburgh. This has more to do with how isolated we had become in our Highland village, than with a full diary of glittering events. But by our

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58 See Internet Movie Database entry for details: <http://www.imdb.com/title/tt0825232/>

standards we've been pretty busy ... We've ticked quite a lot off our 'things to do in Edinburgh' list. (Blog post, Social Life, day 187)

The blog post goes on to list cultural highlights, visits to monuments, art galleries and outings in general. Before we met, Jane had been an enthusiastic hill walker having scaled more than half of the Scottish Munros. As a keen, though less gallowalker, I had previously found the perfect hills in the Pentlands, to the south of Edinburgh. My first real hill walks were there with my mother. We revelled in the delight of being so near to the city while in the middle of a grouse moor. Jane is honest with her initial view, "Purists may mock the Pentlands (I used to) and draw invidious comparisons with classic west coast ridge walks" (Blog post, Small Hills and Sock Mountains, day 106). One of the attractions of the flat is "Our living room has grand views of Capelaw and Allermuir Hills in the Pentlands (which are definitely to be ascended ere long)" (Blog post, Indoor Camping, day 62). This is a life not so much diminished by illness as one that has accommodated it.

Being in, with or near nature is a recurrent theme in many blog entries. Even while recovering from the initial diagnostic laparoscopy, Jane wants more than just fresh air:

It took a few days to recover so that was just small walks maybe just round the block. Then I took her in the car to the nearby park and walking round the pond. She drew such strength from being out in the fresh air, from seeing birds, she wanted to see nature, to see birds, to see plants, to see trees and to be out in the countryside. (Interview 2, 13 August 2013)

In Edinburgh, visits to the Botanic Gardens are a regular feature to assuage clinic visits or the enforced inactivity of a treatment session "The day before the first [chemo] session [Veronica] took me to commune with the yew trees" (Blog post, Silver Linings, day 45). The symbolism of yew trees as the source of the chemotherapy agent, Taxol, was noted in Section 5.2. We both use the gardens as a living reference for plants and trees, sharing a common interest in horticulture. In turn this aesthetic pleasure is shared with others:

We took [my brother and partner] to the Botanic Gardens and showed them all our favourite trees. There's something particularly special about showing a special place to someone else and appreciating their appreciation. (Blog post, Portobello, day 47)

When she starts to feel the treatment is having a beneficial effect, the walks become braver:

This morning we climbed to the top of Allermuir Hill, the focal point of our living room view. Only 1619 feet high but all achievements are relative

and I was very pleased to make it to the top and back down again, feeling stronger and more like myself with every step. The wind was exhilarating to the point of almost blowing us off our feet and the southern Pentland ridge emerging tantalising as we climbed promises much exciting walking to come. (Blog post, Top of the View, day 89)

Two months on and into the now weekly chemo regime, her enthusiasm remains undiminished: We had another grand walk in the Pentlands last weekend – 12 km through the Green Cleugh to Scald Law. Sunshine, blue sky and light winds, slight autumn nip in the air, crisp burnished colour all around. It felt really good to be on a genuine expedition, returning to the car as the sun was disappearing into the west and the sky was turning from pale blue to indigo. (Blog post, Bimbling Along, day 150)

The connection to and participation in nature is paramount; illness is transcended, diminished and almost forgotten by the exhilaration of climbing a hill. Jane views a bigger, wider world with distant vistas and far horizons; her insignificance and situation can be seen in context. This is Jane's real bucket, the beam on which she balances life with death. Her accounts of nature and the landscape are not confined to the macro world of hills and valleys but imbued with details of birds spotted, flowers sniffed and trees beheld. These are her companion stories of living life, reinforced in the pleasure of telling the story. Yet if she is a storyteller wounded (Frank, 2013) by disease, are her stories really just a simple nature notebook to assuage the severity of her illness? These accounts also exemplify a *return enhanced*. The interplay between the intense appreciation of the effulgent experience of nature in counterpoint to the darkness of disease.

Conventionally, the call for stories in response to illness may serve two purposes: as reparation for the damage of the illness to the self, and secondly as a repository for the public news broadcasting system (Frank, 2013). Previously I believed Jane's use was the latter, her mechanism for keeping the support circle apprised. However perhaps the more essential purpose was a self-maintaining function. Story-making is a craft act of shaping and honing that can entertain and distract an active mind for hours. It was what enabled her to sit passively through long treatment sessions or hours of recuperation on her couch throne. From either a view was essential "I sat in a reclining chair by an open window above a flower garden" (Blog post, Silver Linings, day 45) and "certainly a huge relief to be writing this from my throne by the window with my view of the hills" (Blog post, Breaking out of the Hospice, day 323). In the first quotation she is enduring treatment and in the second enjoying the sanctity of literal *at-homeness* (Galvin & Todres, 2011b). On both occasions, story-making was her companion. Later in this chapter I



will investigate the work that stories do. Here it is worth noting that while storytelling is a dual act of reaffirmation (Frank, 2013) for both the self and others, there is a prior stage as “Jane was very good at rehearsing what she wanted to say” (Interview 2, 13 August 2013). It is not possible to access the inner workings of embryonic stories but the process of story-making may be at least as important as the product.

## 7.4 *Analysing Narratives of Illness*

Frank’s influential work on narratives of illness (Woods, 2012) has come to define how such accounts are now interpreted and understood. Consequently, having found his triad of illness story types: restitution, chaos and quest (Frank, 2013), it becomes difficult not to then view illness writing through these lenses. The illness story typology interpellates as we are “made to constitute our objects in particular ways” (Law, 2000: 16). However, before expanding on this typology, other interpretations including Robinson (1990), Hydén (1997) and Bury (2001) merit consideration. Robinson (1990) sought to address the ambivalence with which personal illness accounts were viewed at that time despite the quality of the deeply meaningful content and the insight provided into the experience of illness. He notes “these very qualities seem to make any systematic, valid and reliable attempts to create generalisable propositions difficult, if not impossible” (Robinson, 1990: 1173). Using a three dimensional approach which considered in addition to personal narrative, the illness trajectory<sup>59</sup> and the social career of the sufferer, Robinson identifies three contrasting narrative life trajectories that can be associated with chronic illness:

A progressive narrative moves towards the personally valued goal(s), and a regressive narrative moves away from such valued goal(s), and a stable narrative evaluatively sustains the same position in relation to the valued goals throughout the narrative sequence. (Robinson, 1990: 1176)

In contrast, the relational aspects of the narrator, the narrative and the illness are recognised by Hydén (1997) who emphasises that the three may not necessarily be one and the same. An account of the personal experience of illness will combine all three to produce a story of illness as narrative. In contrast, a medical account will convey a narrative about the illness between professionals. On occasion the narrative itself is a manifestation of illness as a result of brain injury or mental illness. In this thesis the relational aspects are evident in Part Two where Jane and I narrate her illness *as* a narrative interspersed with additional accounts *about* her illness

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<sup>59</sup> See Section 2.2.2

narrated by various health professionals. Another interpretation is as a framework for the analysis of the form and content of chronic illness narratives (Bury, 2001). Three types of narrative form (Bury, 2001: 256) are identified as:

- contingent: explanations of illness, its causes and the practical effects of symptoms
- moral: accounts of the changing relationship between the person, the illness and social identity
- core: connections between the lay person's experience and deeper cultural levels of meaning attached to illness suffering

Bury (2001) expands his core type to accommodate both Robinson's (1990) narrative directionality given above and genres such as epic, heroic, tragic, comic or ironic, as "devices for structuring and giving meanings to stories" (Kelly & Dickinson, 1997: 266). The need to take the illness narrative as a whole and in context is emphasised as "attention to narratives has the ability to provide clues to the ways in which body, self and society are linked in late modern cultures" (Bury, 2001: 282). The comparative analysis of illness narratives therefore has the potential to provide important insights into many aspects of the illness experience. However, in the context of this study while comparisons can be made to other similar or contrasting narratives and the studies cited above have provided interesting perspectives, I now want to return to Frank's (2013) typology and his 'insider' perspective. My purpose here is not a sociological interpretation of chronic illness as related through researcher interviews. It is to understand the autobiographical nature of life during an illness experience and the relationship between the different stories told about that experience. Frank's typology provides a useful framework for the interpretation of self-generated, as opposed to research-occasioned, accounts of living with and beside an illness experience.

## **7.5 Working Stories**

The three dimensional narrative inquiry space (Clandinin & Connolly, 2000) with its intersecting axes of interaction, continuity and situation, was introduced in Section 3.4.6 as a structural device. A similar conception is the way in which a set of stories not only intersect with but also interfere with each other (Law, 2000). Connections may be found in similar stories but there may be a disorderly aspect such as when a temporal sequence is either misremembered or perhaps has its chronology deliberately distorted for some other reason. However, it can be

difficult for the intended audience to follow a story if its telling is too disordered, so some organisation into, for example foreground and background, is necessary. Frank (2010) suggests there is some fine-tuning to the work stories do which involves the use of a default guidance system with two axes. The first axis connects personal understanding with affiliations, while the second connects what can be good about life with what makes it dangerous (Frank, 2010: 48). The following extract illustrates the system in action:

the oncologist broke the news ... that the CT scan showed the tumour had not apparently shrunk very much ... He asked if this news surprised me. I think I nodded, while actually it would be more accurate to say that it rather floored me. Because I had been feeling so much better, and stronger, I was sure the chemo was working and that surgery would be scheduled soon (Blog post, 'A Different Mindset', day 98)

The first personal-affiliation axis receives the news of the CT scan results by using a coping story of appearing to be in unsurprised agreement (nodding) while concealing the real response. The second good-dangerous axis reveals the misleading nature of feeling better and raising expectations while hiding reality. The full version of this quotation appears in Section 5.2 where the interpretation focused on the sequence of events and their effect on Jane; the analysis was on the *content* of the story, not on the *work* of the story.

Returning to Frank's typology, the restitution story is founded on the statement "Yesterday I was healthy, today I'm sick, tomorrow I'll be healthy again" (Frank, 2013: 77). It serves to distance mortality and reinforce belief in the efficacy of the medical treatment. The chaos story is in sharp contrast to and opposite from restitution. It is hard to hear an experience without sequence or causality that "traces the edges of a wound that can only be told around" (Frank, 2013: 98). Reading tales of restitution and chaos can be difficult, hard work for the reader. Quest stories are more comfortable to read as they offer a coherent account of acceptance and distancing the chaotic disruption of illness. They utilise illness as "the occasion of a journey that becomes a quest" (Frank, 2013: 115), or the *Bildung*<sup>60</sup> of the *Bildungsroman*. Quest stories are the type with the greatest range in the genre of illness stories. Frank elaborates on this aspect in two ways. First, as the narrative structure of a heroic journey with its three stages of departure, initiation and return "best described by Joseph Campbell in his classic work, *The Hero with a Thousand Faces*" (Frank, 2013: 117). The second way in which Frank extends the specification of quest stories is by suggesting they may have three different facets: memoir, manifesto and

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<sup>60</sup> This observation has also been made by Strawson (2004: 441).

automythology (Frank, 2013: 119). I will return to the heroic journey once these features have been elaborated but first the typology may be easier to follow using my diagrammatic interpretation:

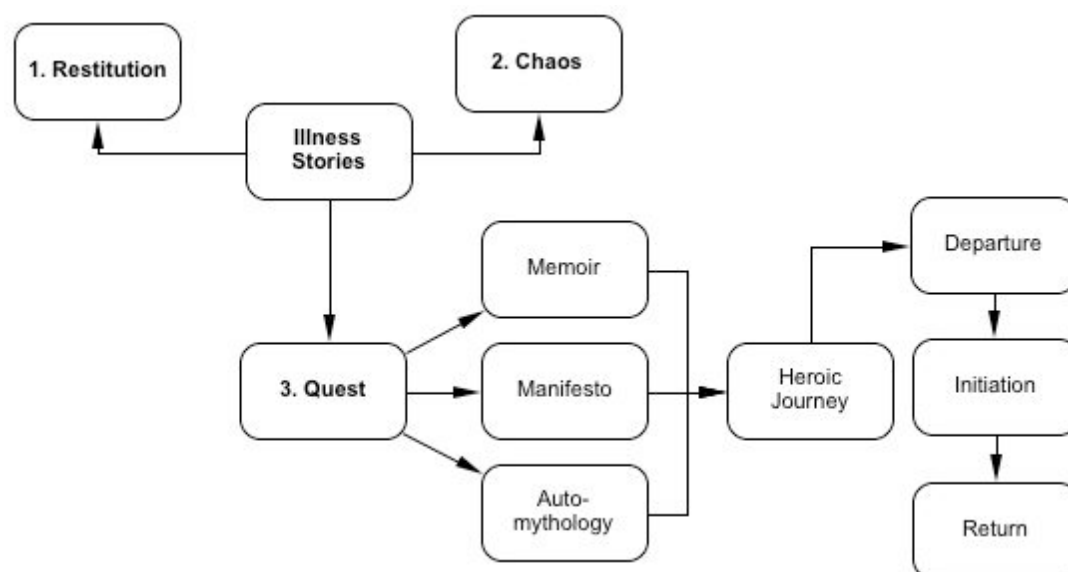


Figure 7.1 Typology of Illness Narratives<sup>61</sup> (Frank, 2013)

The memoir is perhaps the easiest form in its depiction of life with the incorporation of illness. Pathography is a term used to describe a published account of the hopes and fears of living with illness (Hawkins, 1999) Such books may also act as a guide to treatment and help to shape the reader's understanding of the course of the disease. In a review of her earlier book, *Reconstructing Illness: Studies in Pathography* (Hawkins, 1993), Frank (2013) notes that the most popular pathographies have celebrity authors which raises issues of voyeurism and the commodification of the illness experience, that is to benefit financially from the story. Nevertheless, Frank finds illness memoirs to be the most gentle of the quest narratives as their popularity with the public appears to confirm.

The manifesto type of quest story is the opposite of the memoir and therefore generally makes uncomfortable reading. The style is usually emancipatory, giving a voice to suffering and the truth of illness that must be told. Susan Gubar's *Memoir of a Debulked Woman: Enduring Ovarian Cancer* (Gubar, 2012) is part memoir and part manifesto in its telling of one academic's account of her personal suffering and surgical evisceration. I found it too uncomfortable to read

<sup>61</sup> This figure is my own.

and too close for comfort. I have read excerpts, feeling galled and frustrated by her brutal honesty. While I can empathise with her plight and respect her sincerity, I am uncertain who the intended audience would be for such a work. It is a testament of survival and raises the issue of public awareness of the disease but I would not recommend it to a woman with ovarian cancer. However, reading some of the online reviews of the book suggests that sufferers, carers and many others, do find the text inspiring and helpful. Thompson (2007) suggests that women with ovarian cancer want to talk with fellow sufferers and will therefore seek women who they feel are able “to hear as well as provide recognition” (Thompson, 2007: 347). The third type of quest is the automythological type and tells a story of reinvention as an illness response. It is more than mere survival, it is rebirth. It can be recognised by the use of powerful language, such as destiny and regeneration, to tell legends and mythological interpretations of the illness course.

Frank’s (2013) real purpose in proposing his typology is not to suggest a general unifying type but to assist the reader in ‘listening’ to the story. I have admitted my own difficulty in reading illness stories so how does the typology help to listen to Jane’s story? Before I address this question, there is another point to note “In any illness, *all* three narrative types are told, alternatively and repeatedly” (Frank, 2013: 76, original italics). Similarly, Bury asserts “whatever narrative form may be identified in analysis, many accounts move from one to another” (Bury, 2001: 280). In my overwhelming desire to tell the story of Jane’s illness, I did not attempt to analyse Jane’s blog posts. This is not an excuse but a feature of the emergent nature of the study as a contemplative inquiry. However, Frank makes a valid point and examples of all three narrative types can be heard in Jane’s writing.

## 7.6 *Listening to Jane’s Stories*

The blog post *Silver Linings* (day 45) was the longest and written three weeks after diagnosis. The opening paragraph<sup>62</sup> accords with the literal definition of the restitution story. This is exemplified in the three phrase sentence which begins *Yesterday I was healthy*, and Jane writes “Our little world turned upside down and it’s taken a wee while before I’ve felt able to write about what’s been happening”. It is the first clause, the world of health turned upside down, to ill health that signifies the start of restitution. The second phrase, *today I’m sick*, follows immediately in her next sentence “In short: I’ve been diagnosed with ovarian cancer”, and is self-explanatory. The final phrase, *tomorrow I’ll be healthy again*, comes after a blog page of diagnostic tests and procedures “Treatment is to be four cycles of chemotherapy in the first instance, which they

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62 See Section 4.3

hope will shrink the tumour to an operable size, then a hysterectomy”. In telling this restitution story, Jane is distancing herself from her own mortality despite her explicit description of the extent of the disease “I have a Stage 3 serous tumour which started on my left ovary, has munched its way through most of my uterus and ‘involves’ the bladder wall and the rectum”. Her focus is on being restored to health by the treatment plan.

However, there are also traces of the edge of chaos, the second illness narrative plot type, suggested by the delay in writing the account of what has happened. Following the uncomfortable business trip to London, she writes “After a couple of sleepless nights we decided something had to be done”. Her reader is spared my recollection “She was miserable with the pain in her back, with the tightness in her abdomen, with the feeling unwell” (Interview 1, 9 July 2013) and diary entry “Woke me at 4.30am in severe pain”, (Personal diary, day 3). Jane was too conscious of her audience and the informative intention of the blog, to write anything that might cause additional anxiety and upset. At the time I had a strong sense that ‘*no one*’ (Frank, 2013: 101, original emphasis) was in control. We felt out of control not knowing what was wrong with Jane; when help was sought, respite was temporary. Jane’s account ignores the chaos by adhering to narrative format as sequence and consequence (Riessman & Speedy, 2007) diverting attention to the ‘lovely young doctors’. Chaos is the embodiment of suffering and can only be described by the sufferer in oblique terms. It was perhaps because the chaotic aspects were not told by Jane that I felt that there was something missing from her narrative that needed to be told, that I had to tell.

In effect, part of my role as her primary carer was at best to prevent anything chaotic occurring but if it seemed imminent then to absorb and deal with it. A difficulty may then arise for the carer when they do not have time to resolve their experience of chaos. It becomes their embodiment of their partner’s disease. There are two other explanations for the lack of chaos in Jane’s account: firstly she was all too aware of the sensibilities of her audience. And secondly, as Riessman has recently observed through her own personal experience, “Omissions are one way to exercise control over the uncontrollable” (Riessman, 2015: 8). So when the chaotic does happen, Jane does not write of the experience herself. One particularly chaotic episode was the insertion of the permanent abdominal drain, described in Section 6.2. Chaos ensued when the attendant staff chose not to heed my advice that Jane should not be laid completely flat. They did, she vomited, everyone flapped. If the chaos story is “an anti-narrative, so it is a non-self story” (Frank, 2013: 105), it is then neutralised when a coherent story is told. In Jane’s version of

the drain insertion, there is no suggestion of chaos nor of her suffering during the procedure. Instead she writes “I now have a permanent drain fitted which makes ‘little and often’ drainage possible” (Blog post, *Catching Up*, day 272). This could be read as a restitution story but Jane’s interpretation is more likely to have been as a binary synthesis of chaos being subordinated by order.

The third illness narrative type, the quest story, is the most complicated as the illness is expressed as a journey and may have different facets to its plot structure: memoir, manifesto and automythology (Frank, 2013:). Quest narratives enable the sick person to tell their story. In a restitution narrative the action is with the treatment regime; in a chaos story the self is consumed by the suffering and cannot tell, but with a quest the story is in the foreground. Consequently they are the most common type of published illness accounts, often portrayed as a journey with or through illness. The narrative structure provides a framework for the sick person to accept their illness and then use it to find an alternative way of being. The predominant style in Jane’s writing is that of memoir where she writes extensively about everyday life with occasional illness bulletins. She describes a figurative journey as a passage through a life that foregrounds the present but makes few references to the future. Perhaps this is because she soon realised there was little chance of remission or sustained restitution. Jane was teleported to Susan Sontag’s “kingdom of the ill” (Sontag, 1978: 3); the expression is ironic in itself for someone who disliked illness metaphors. Once in this new place, it was interesting “Chemotherapy is a fascinating process” (Blog post, *Silver Linings*, day 45) but also engendered feelings of being “a bit tired and paranoid if anyone sneezes in my proximity” (Blog post, *Silver Linings*, day 45). This was not so much a land to journey through, as a place of work. Jane’s new job was to balance the exhausting clinical interventions by sitting on her ‘rock’. The work done in this place was healing self-restoration, making herself whole to assuage the effects of the illness and its treatment.

There are many examples in her blog of real journeys, the distance that can be travelled in a day, an outing or a day trip. Unsurprisingly, given her fondness for rugged landscapes and hill-walking, her preferred metaphor was “There are many ways up the mountain. Other people can help – describe the landscape, suggest routes, provide kit and provisions, accompany me for part of the way – but I take the path myself.” (Blog post, *A Different Mindset*, day 89). This is where the temporal and situational context is helpful. This quotation comes early in the Illness Period when Jane was no longer relying on others to do the healing work. But she had to find a way to convey this change in direction to her readers. At the start of her illness Jane had devolved

control to the health professionals. It took time for her to work through her internal, personal chaos before she could resume full control.

Returning to the conception of the quest narrative as a heroic journey (Campbell, 1949/2012), the three stages of departure, initiation and return, equate with van Gennep's (1967) 'rites of passage' not least because Campbell made extensive use of the concept in his own work. In this context, Frank suggests a recursive process where "the journey is taken in order to find out what sort of journey one has been taking" (Frank, 2013: 117). In other words it is a quest to find purpose despite being ill. This suggests a reflective element, a story that is written at some later point perhaps after treatment, recovery or remission. My point is that Jane may have seen her collection of blog posts as a traveller's account of her journey through the time she was ill. However, while "illness narratives are by nature ambiguous because they do not have a clear and foreseeable end" (Hydén, 1997: 60), the ambiguity in Jane's story was magnified because it would end with her death. For Jane the blog was a bulletin board of her restoration work as a 'netoir': my portmanteau word for an *internet memoir*.

The two remaining types of quest narratives are manifesto and automythology. Manifesto stories are those that tell a prophetic truth. Frank (2013) uses Audrey Lorde's account (Lorde, 2007) of her refusal to wear a prosthesis following a mastectomy as an example. In similar vein, Jane declined to wear a wig following her chemotherapy-induced alopecia:

I'm now magnificently bald, by the way, although some grey fuzz has started to reappear which looks and feels a bit odd. A bit self-conscious, I've been alert to people's reactions – some give me a big broad smile, some look away, most don't seem to notice. Being bald is only a stigma for women, of course (Blog post, Indoor Camping, day 62)

Jane's prophetic truth was to reaffirm herself as a woman and not as a cancer victim. Furthermore, the quest manifesto "asserts that illness is a social issue, not simply a personal affliction" (Frank, 2013: 122). Another way in which a quest manifesto can be interpreted is as a public policy statement as suggested by this:

One of the things we found most disconcerting about my cancer diagnosis was the official advice effectively banning vitamin supplements. We had what we then considered a pretty healthy and well-balanced diet, supplemented with a carefully researched and tailored regime of vitamins and minerals. It seemed counter-intuitive for me to stop all supplements immediately, at a time when my body was particularly vulnerable, on the basis that the medical profession had no evidence of the extent to which



vitamins might interfere with the effects of the chemotherapy on the tumour. Spot the double negative? ‘We don’t know if it might not work’. When you’re that scared rabbit in the headlights of the doctors and nurses and they are saying that vitamin C might encourage cancer cells to grow, and live yoghurt might introduce infection to your immunocompromised gut, you do what they tell you. More or less. At least to start with. (Blog post, Coping with chemo, day 159)

In this example, Jane has reclaimed her right to participate in her treatment in her own way. This is a call for a partnership approach to her care where she would be an active participant and not just a passive recipient of the treatment regime. It can be difficult to read illness stories as anything other than a sad tale of triumph over adversity or as a heroic battle. While the above excerpt is about fighting the good fight, it is also one of preservation. Saving and salvaging what remains of the disease and treatment ravaged body is a quest for living.

The final type of quest story is that of automythology where the storyteller does not simply survive their illness but is reborn in the process (Frank, 2013). There are two instances of reinvention in Jane’s illness narrative. The first concerns her own creation, the chemo ‘bunnet’, a soft skull cap. It had a dual purpose: to keep her bald head warm and to provide some style for her otherwise bland appearance. In addition to the loss of head hair, chemotherapy-induced alopecia renders the entire body to a hairless state (Jayde et al, 2013). While this is hardly an issue for a clothed adult, the loss of eyebrows and eyelashes can be too stark a contrast, rendering the face featureless. By wearing a colourful little hat, Jane reinvented her appearance to reflect the colourful and amusing character that she was trying to maintain. The myth in this reinvention was that in reality, she found the lack of definition to her face unbearable if she saw her reflection in a mirror, bunnet or not.

The second example of myth-making had emerged quite naturally before she was ill “[Veronica] made Epiphany Cake on the appointed day, and it came to pass that I once again received the bean, so normal royal service has been resumed for the year to come” (Blog post, Festive Family Favourites, day 212). The cake is a European tradition that we had acquired in Belgium when Jane had received the bean the previous year. A cake containing a bean or small ceramic figure is made to celebrate the Christian festival of Epiphany. When the cake is cut, whoever receives the bean is king or queen for the following year. Belgian bakeries selling the cakes supply a gold paper crown for the royal personage. So, it was a family joke that became a useful metaphor for treating Jane in a special way. If she was queen, she had royal prerogative to command whatever

she wished and to be attended by her loyal subjects. It was a myth that she willingly participated in and to some extent encouraged but never exploited. There are various references to Jane as queen or royalty in correspondence with my sister. Being royal had various advantages such as not being required to do household chores and always having first choice of outings or entertainment. In the later stages of the disease, when eating became difficult as a result of abdominal swelling, being royal made food whims and fancies easier:

Sometimes my requests are reasonably adult (I want sushi), others amusingly childish (chips, cola, chocolate ice cream). I can spend much of the afternoon deciding whether I'd rather have my hot smoked salmon peppered or honeyed, and basil or chives in my avocado salsa (with chips of course). (Blog post, *Catching Up*, day 291)<sup>63</sup>.

All of these requests were indulged and provided a useful distraction from the grim reality of only being able to eat very small amounts. Interpretation of the myth also provides an insight into our respective roles as queen and heroic carer. I could cope with all that I had to do in caring for Jane if she was my queen and I was her loyal servant. We were “a relationship in which each understands herself as requiring completion by the other” (Frank, 2013: 150). I did not have to think of having empathy for Jane and her situation, we were interdependent in our mutual need for each other.

By using Frank's typology of illness narratives, other aspects of the stories recounted in Part Two have been identified. However, some question the effect of using such a typology as it promotes a particular model of the self (Woods, 2011). Additionally, there is a normative assumption pervading the medical humanities that the drive for narrative is healthy and desirable. As a testimonial form, the creation and performance of the illness narrative allows the ill person to become “the hero of her own story” (Woods, 2011: 75). But what if narrative is mistaken for life (Woods, 2012) and silence is equally important? The core of Frank's typology suggests that restitution stories are used by those in denial and obligated to medicine. Illness is transformative when it is either as a quest for the better or the chaos of becoming worse (Woods, 2012). Yet not everyone facing illness is called to narrative and some argue it may not even be in our best interests (Strawson, 2004). To then misinterpret silence as narrative failure may be to miss the real phenomenological opportunity to understand illness through other forms of self-expression (Carel, 2011; Woods, 2011). Therefore, while Frank's typology has been useful here in ‘listening’ to other aspects of Jane's illness, its use was not “intended as a pigeon-holing device” (Mishler,

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63 See Section 6.3 for a longer extract of this quotation.

1995: 117) and was to instead learn from other approaches. I have suggested that Jane's narrative was one of restoration, as a counter-balance to her illness and its treatment. To read it wholly in Frank's terms would be to misinterpret it first as a restitution denial of illness and dying, then as a quest for living. But this would be to fall into the Buddhist attachment trap<sup>64</sup> and be deluded by the illusory nature of her writing. She was in no doubt that she was dying and writing about living was not the illusion. However, some family members did interpret it as such and were then apparently shocked to learn of her imminent demise.

## 7.7 *Stories of Death and Dying*

To conclude this chapter, I want to raise an issue that has troubled me from the outset of this study. Jane and I knew that we were fortunate to have each other: me to care for her and her to need my care. But we were conscious that for many people facing a life foreshortened by illness, it was not so easy. Whether it be for family pressures, responsibilities as carers of children, ageing parents or some other reason, one half of a couple devoting themselves to the care of the other may be a luxury. Being *at home* emerged in Part Two as central to the well-being of the sick person. Over the course of this study, I have been particularly interested in published accounts of two people as a couple, where one of them is facing illness. Historically, the sick person was cared for at home, on occasion even surgical operations were performed in the bedroom. Health care became organised and institutional, not least to halt the spread of infectious diseases such as tuberculosis<sup>65</sup>. Now the sick, frail or dying person is often cared for in an institutional context, sometimes hospital but often a care home or hospice. The knowledge and confidence to provide nursing care in the home is a lost art. The solution to health care problems, both actual and anticipated, is increasingly pharmaceutical. The move towards consumerism in healthcare coupled with developments such as expert patient programmes are consistent with and not contrary to the interests of the pharmaceutical industry (Williams et al, 2011). Nowadays if you feel you have flu, you self medicate and continue working or possibly take a few days off work. But you are unlikely to be nursed at home until you feel well again.

At the end of life for those with solid metastatic tumours, there is evidence that chemotherapy treatment will continue to be offered and used despite the likelihood of a reduced quality and duration to life (Davies, 2014). The situation is compounded by public expectations of the efficacy of the latest treatments and the reality of what can be delivered by health care services.

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<sup>64</sup> See Section 7.2

<sup>65</sup> See Section 5.4

The demand for new anticancer drugs, despite their marginal benefits, can consume the limited research resources for other debilitating conditions. The focus on the pharmaceutical treatment of cancer has also meant that there is less research into other non-drug therapies (Davies, 2014). There are many ways in which the dying experience might be enhanced, both pharmaceutically and by other means. However, enhancement is a contested term used “to denote going beyond treatment or health” (Williams et al, 2011: 718), to be better than just well, whatever that might mean. In this context the enhancement of death and dying may appear to be at odds with the therapeutic desires of the ill person and their family. However, the opportunities for a more aesthetic experience when near the end of life do exist but I suggest they are poorly understood and under researched. I will return to this issue in chapter eight.

## **7.8 *Compassion in Care***

Compassion is a key feature of healthcare but it has become a subject of concern, particularly with regard to older people (Stenhouse et al, 2013). In the context of hospice volunteers, Fisher and Freshwater (2014) suggest that the rise of new public management (NPM) (Hood, 1991) is a key factor in the lack of compassionate care as highlighted by the Francis Inquiry<sup>66</sup> into the failure of an NHS trust. NPM can be understood as an economic movement that emerged post World War II and characterised by user choice, transparency, incentivization and managerialism. These principles are in sharp contrast to the traditional bureaucratic and ex-military ideas of good administration and hierarchical organisational structures (Hood, 1991). In a study of hospice volunteers Fisher and Freshwater (2014) suggest that the way to restore the compassion to care is by creating a subjective sense of physical, social and emotional well-being. This can be achieved as:

a ‘sociability of care’ [that] might be generated through aesthetic rationality and that the potential value of the latter should receive higher levels of recognition within public and social care organisations. This is perhaps especially pertinent to the care of older people and people with chronic conditions, where the emphasis on present well-being (rather than on future oriented ‘cures’ or outcomes) should be the main concern. (Fisher & Freshwater, 2014: 772)

The authors blend Simmel’s understanding of sociability as the tactful “play-form of association” (Simmel, 1949: 255) or social interaction for the inherent pleasure of companionship, with

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<sup>66</sup> The report of the Francis Inquiry is available at: <http://www.kingsfund.org.uk/projects/francis-inquiry-report>

Bologh's notion of "aesthetic rationality" (Bologh, 1990: 240) that adds value through its appreciation of domestic and communal relations. Another, related point highlighted by Fisher and Freshwater (2014), is the concept of a "philosophy of the present" (Davies, 1997: 566). In a study of people with a positive HIV diagnosis, living in the present was found to be curiously liberating as a freedom from everyday existence and battling for a future. People who no longer feel they must plan for a long life are better able to enjoy daily life. In my experience, a similar sense can be found among those with a diagnosis of advanced cancer.

Living in the present was identified in contrast to "living in the future" (Davies, 1997: 567) and "living in an empty present" (Davies, 1997: 568). Ezzy (2000) has combined Davies' (1997) temporal orientation theory with Frank's (2013) illness narrative typology, leading to an interesting insight. The temporal orientations map onto the narrative types as depicted earlier:

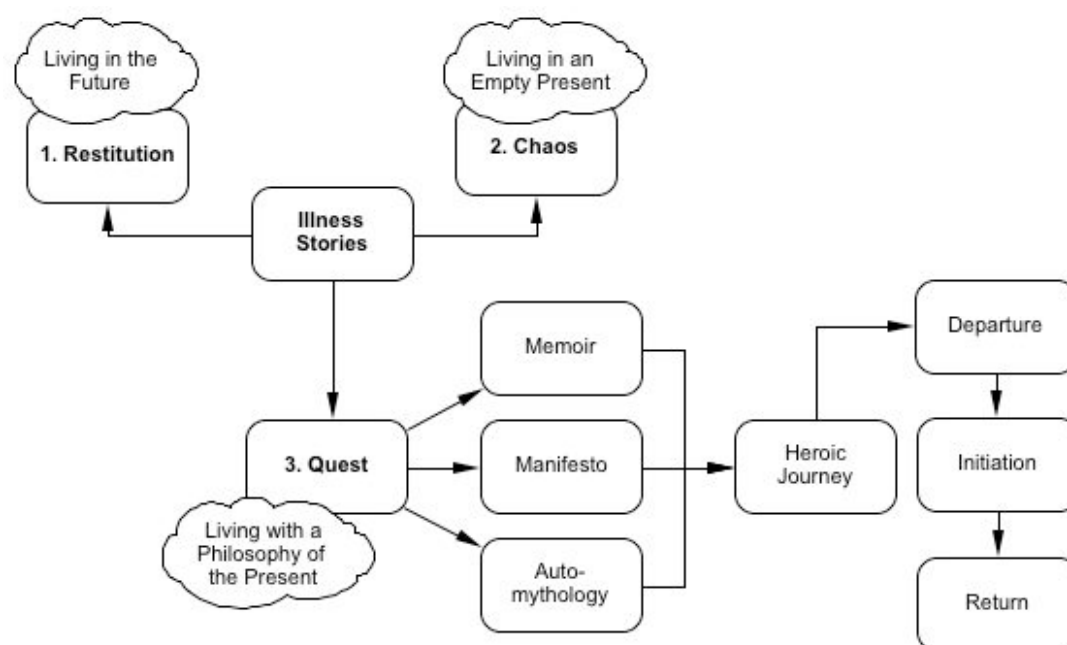


Figure 7.2 Amended Typology of Illness Narratives (Ezzy, 2000; Frank, 2013)

The heroic quest is oriented to the future with suffering understood as being necessary for personal development. If the hero is living with a philosophy of the present, they are freed from the quest for personal growth.

Typically gathering illness stories relies on qualitative interviews. Ezzy (2000) interviewed 46 people with HIV; Thomas-Maclean (2004) twice interviewed twelve women with breast cancer; and Whitehead (2006) interviewed seventeen people with chronic fatigue syndrome as many as

three times. These studies all made use of Frank's illness narrative typology as an analytic framework with data that was inevitably gathered on occasions that fitted the research timeline and not the respondents' illness chronology. The point being that it is unusual to study narratives of illness that are created concurrently with their illness period; inevitably interviews are post diagnosis or treatment. Whitehead acknowledges that her illness narrative data described lived time, were in progress and unfinished, reflecting that "interviews conducted earlier, or later, in the illness experience could paint a different picture" (Whitehead, 2006: 2244).

In a comparative study of people living with cancer, chronic kidney disease (CKD) or HIV, a total of 113 in-depth interviews were conducted with 32 participants over three years (Shields et al, 2015). The authors claim that narrative accounts of life-limiting illness were found to be poorly described in the literature and that generalisations should be avoided by focusing on contextualised and person-specific narratives. A feature common to all three groups with cancer, CKD and HIV, was uncertainty which ebbed and flowed between critical disease points. This uncertainty led to "re-crafting of narratives across all of the illness groups as participants navigated and re-storied their illness journey" (Shields et al, 2015: 214). Interestingly, it was the cancer group who employed perceptible turning points in their narratives as they negotiated the moves from diagnosis through intensive treatment to living well after treatment. However, this finding does not quite equate with the clear turning points in Jane's narrative. The first came after chemotherapy had begun<sup>67</sup>, "I had a bit of an epiphany during the consultation with the herbalist. Actually it was a bit of a crack-up, or a breakdown" (Blog post, A Different Mindset, day 98). This was Jane's recognition that while the cancer was not her fault, she could take control. The second turn<sup>68</sup> was when:

... my lovely oncologist, who, lovely as he is, is not able to offer a ready solution to my current problem. The tumour is too large, and too widespread, for surgery to be an option (certainly not at present, and probably not at all). Additional chemotherapy is unlikely to have any positive effect on the malignancy at present either. (Blog post, Everything is Going to be Alright, day 247).

Based on this analysis, I suggest that what has been interpreted as a turning point at diagnosis when a "rupture or disjuncture in life took place, and then life was defined by 'before and after'" (Shields et al, 2015: 211) is actually an abrupt halt. Diagnosis is not so much a turn sign as a red

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<sup>67</sup> See Section 5.3

<sup>68</sup> See Section 6.2

light. The stop sign marks the threshold to the sacred world of serious illness with its proximity to life's finitude. The illness may be treatable, become chronic and make re-entry to the secular world possible for someone as then forever ill. With life-limiting illness the crossing is permanent, a point of no return from the sacred world of dying. However, in my configuration turning points do also occur; the first is when the person is able to regain some ownership or control over their situation. It is a return enhanced to living having been reminded that life is finite. The second turn may be specific to people with a diagnosis of advanced cancer at the outset and comes with the shift to palliation despite the recommendation of a more blended approach to palliative care (Murray et al, 2005). Health care provision may well be seamless but I believe there is an identifiable moment when the ill person turns full face to death. This may be some weeks or even months before actual death and is recognisable although not always perceived.

## **7.9    *Illness Stories in Two Voices***

In my explorations of narrative accounts of illness, I have been struck by the apparent lack of studies of collaborative writing in illness narratives. I am not referring to collaborations between researchers but those between the sick person and, ideally their partner, or primary carer. There do not appear to be any reported analyses of naturally occurring co-authored narrative accounts of illness. Studies have investigated the service user experience of palliative care provision (Cotterell, 2006; Cotterell et al, 2009) or the needs of the family carer in a palliative setting (Newbury, 2009; Payne et al, 2012). It has been suggested that emotionally charged narrative accounts of death and dying should be treated with caution during analysis as it is easy to drift from the emotional surface to drawing theoretical conclusions based on the emotional response of the investigator (Eva & Paley, 2006). Nevertheless, there is an increasing interest in joint interviewing (Morris, 2001; Polak & Green, 2015) and in the co-construction of illness narratives (Radcliffe et al, 2013). The presentation by the couple of a united front (Gerhardt, 1999) in response to the adversity of illness is a common feature although women tend to dominate discussions (Radcliffe et al, 2013).

In addition to the benefits of joint interviewing that includes the possibility of making sense of shared experience together (Mattingly, 1998b), the contextual nature of care practices are focused through the "foregrounding of the intersubjective and heteroglossic nature of illness experiences" (Sakellariou et al, 2013: 1567). Essentially, intersubjectivity is the shared experience of lifeworlds which can extend into the adoption of others' language or heteroglossia. For

example, in the blog post *Silver Linings* when Jane first describes her illness, she uses clinical and anatomical language, and by the end the intersubjective nature of our relationship has been detailed and then summarised as “We’re a team, and we are a winning team” (Blog post, *Silver Linings*, day 45). While similarities can be identified from joint interview studies, I was looking for consciously co-authored accounts that were more in the style of collective biography (Davies & Gannon, 2012). This form of collaborative writing and biographical memory work has developed over the past decade. As a method, it “does not look for a uni-directional oppressive effect of *discourse* on *individuals*. Rather, [it] is conceived as emergent in each moment, moments that are simultaneously discursive, relational, and material.” (Davies & Gannon, 2012: 359, original emphasis).

Having identified an opportunity for future, authentically voiced research, co-authored or concomitant accounts do exist. With hindsight, if I had known at the time what I now understand of narrative inquiry, I might well have suggested to Jane that we embark on a collective biography of her illness. Although she knew that I would write some version of our experience following her death, we missed the opportunity to share the writing work together, to engage in a discourse of our individual and collective experience of Jane’s illness. Gaydos has proposed a four stage “co-creative aesthetic process” (Gaydos, 2005: 254) as a technique for the co-creation of personal, life journey narratives in nursing practice. A similar process has been used to explore the life journeys of hospice nurses (Gaydos, 2004). The four aspects are “engagement, mutuality, movement and new form” (Gaydos, 2005: 257). The process begins with the engagement between the patient and the nurse, in the respective roles of storyteller and listener. Then, in a context of mutual empathy, the emerging story moves back and forth between the teller and the listener with the nurse keeping note of chronology, connections and feelings associated with particular memories. Finally, the co-created narrative emerges and is said to be “healing as the self story is witnessed by a caring person, memories are understood in new ways, and the self story is both confirmed and recreated” (Gaydos, 2005: 259). However, Gaydos describes herself as a visual artist and the final product from her process is a narrative image, not a storied account. Nevertheless, the process is similar to that described for collective biography (Davies & Gannon, 2012).

To date, no studies have been identified that used these techniques to co-create an account of a patient and partner/carer narrative. For that reason, I have drawn on two published examples of collective writing to illustrate the potential of such processes. The first is a co-authored book,



*Cancer in Two Voices* by Sandra Butler and Barbara Rosenblum (1991). It tells the story of the personal relationship between two women; the focus is on Barbara's breast cancer diagnosis, treatment and death. The co-construction was created by Sandra (Sandy) from their journals, diaries and letters, after Barbara's death. The second example was published as two separate books and as newspaper articles in *The Observer*.<sup>69</sup> The art critic Tom Lubbock's *Until further notice, I am alive* (2012) is his personal account of life with glioma, a brain tumour, and its effects on his language. His wife, the artist Marion Coutts, describes the eighteen months leading up to his death in *The Iceberg: a memoir* (2014). She also wrote the introduction to Tom's book (Lubbock, 2012) and played a vital role in assisting him in his desire to write "about my life in public form" (Lubbock, 2012: 135).

The extracts are of necessity brief but they convey the essential nature of the co-created illness narrative. Both Barbara and Tom were aware of the advanced stage of their diseases at diagnosis. I have selected excerpts that illustrate the turning point when they each turn full face to death and also as reflected in their partner's accounts. Sandy and Barbara had decided to go on one last holiday to Florence but the exertion was hard for Barbara as Sandy recalls:

The next day Barbara collapsed from exhaustion. We had left our hotel at dawn to watch the city awaken. Before long I realised that, inadvertently, we had gone too far ... Barbara barely managed to stumble back to the hotel, needing to rest at every corner. She slept most of the remainder of the day, awakening near midnight. As we lay in each other's arms, she talked about her fear and her sense of missed opportunities ... When we both awoke the next morning, fresh from our dreams, we understood we had moved imperceptibly closer to the inevitability of this ending, her death" (Butler & Rosenblum, 1991: 123).

A few days later Barbara writes:

There has been a change in my medical status. Cancer is growing again in my liver. The symptoms are pretty terrible. I have more fatigue than ever before. A profound loss of energy and direction and an inability to be 'present'. I'm more detached, perhaps saying my good-byes in a way. I am just doing what is necessary to survive. My mind and body are doing what they – I – need to do. I cannot stay with my feelings so much. My awareness clicks off when necessary. I must do that to cope with this new reality, death facing me. Me facing death. (Butler & Rosenblum, 1991: 123)

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<sup>69</sup> Marion Coutts: 'There is going to be a destruction... the obliteration of a person', *The Observer*, Sunday 15 June 2014. Available at: <http://www.theguardian.com/books/2014/jun/15/marion-coutts-tom-lubbock-iceberg-extract>

As a whole, the book (Butler & Rosenblum, 1991) is a blend, in Frank's (2013) narrative terms of memoir and restitution. In the excerpts, Barbara's writing indicates a shift to living in an empty present (Davies, 1997) tinged with chaos. Sandy continues to reflect, as she does in much of the book, that she is living in the future, her story will not end with Barbara's death. While their account appears to be written in open awareness (Timmermans, 1994) of Barbara's approaching death, the quotations suggest that the awareness was more akin to conditional openness (Field & Copp, 1999). This mode reflects the transience of the emotional and cognitive responses by patients and their partner/carers to imminent death. Barbara also seems to have moved to the third of the four 'readiness to die' modes, "person not ready, body ready" (Copp, 1998: 388). In her study of hospice nursing perspectives of dying, Copp (1996) proposed a separation between the body and the self indicative of a person's readiness to die. Generally this was characterised as a shift from 'person not ready, body ready' to 'person ready, body ready' but she acknowledged a shift between any of the four modes was possible. Barbara senses her body signalling a readiness to die to which she must adjust and accept. Yet she lives a further eight months until Sandy writes "At exactly eleven-fifteen the next morning, Valentine's Day, you sent me in to the kitchen for some fresh water, smiling up at me with love. When I re-entered our room, just moments later, with herb tea and ice water, you were already dead" (Butler & Rosenblum, 1991: 170).

The many months between Barbara's observation that she is facing death and the actual event, suggest that the actual process of mind-body separation is longer than might be inferred from "the terminal phase ... when the dying person starts to withdraw from the outside world" (Copp, 1998: 385). Specifying the likely duration required for terminal care is a controversial but necessary topic in the planning of palliative care provision (Murray et al, 2005). I will limit discussion to this definition "the management of patients during their last few days or weeks or even months of life from a point at which it becomes clear that the patient is in a progressive state of decline" (Maltoni & Amadori, 2001: 449). However, the authors go on to amplify the weeks and months to up to a year when death can be expected to occur. The lay public may prefer this more prosaic definition "When you reach that place where you have been told – and you believe – that you are going to die within a certain amount of time: that is the Death Zone" (Gould, 2012: 119). Barbara described her sense of detachment which would seem to support Copp's (1998) suggestion of withdrawal over Gould's (2012) desire to accept medical wisdom.

In the second pair of excerpts, Marion describes a clinic visit:

In the consulting room of the diabetes nurse Tom looks very sick. The lighting is aggressive and I see him clearly for the first time in days. Though bright, our house is nowhere as evenly lit as this ... we are both wearing the clothes we got up in not very long ago and Tom looks eroded and shabby around the edges. He is a big, dark garden rose blown out at the end of the season, a hybrid purple and black. His eyes are dulled. His hair is damp with sweat. His silhouette was always dynamic, strangely elastic and crisp for a large man, and kept its energy well. Now he seems loose, his flesh not kempt but wayward, no longer trimmed in tight by the body's pull. Forces other than gravity are at work. Gravity drags down while the cancer pushes out from the centre ...

I observe him. Is he going to fall over? I wonder. He hasn't yet, but might at any point. Is he asleep? Will he be able to get out of the chair again? Getting out of the chair is a complex muscular action that his legs and forearms strain to do. He is a dying man. That is what he looks like. How long has his skin been this pale yellowish-grey? It's as pale as joiner's putty or porcelain unfired. (Coutts, 2014: 182–3)

It was difficult to identify appropriately concurrent entries from the two accounts as Marion's version is not always dated nor in temporal sequence. However, this extract from Tom's book is within a week or two of Marion's above:

Things are very much lost. I can't really write at all, except very late, and very limitedly.

At the moment it's only 7pm. I want to think about my article: about the beginning of this life.

It was exactly two years ago. This life began with my first fit. My immediate symptom was recognised as a brain tumour – with the very first operation – and the fact that my life wouldn't last very long.

My acceptance of death. My gratitude for medicine.

Though the future was always waiting.

And then, rather recently, there have been the growing problems with speech.

And it's very hard on the limbs. (Lubbock, 2012: 140–1)

Marion writes as the artist she is, visually, rich with colour and detailed description. We see the crumpled, decaying rose slumped in the chair and sense her awareness of his dying now being too near to ignore. Tom's writing is one of the last entries he made before he lost the ability to

read and write. With the help of Marion and friends, his essay was published in *The Observer*<sup>70</sup>. Four months later he died, the nature of his illness necessitating hospital and hospice care for the last two months. Marion's description of Tom's death comes slowly over a few pages with scattered interruptions from hospice life and visiting friends:

Tom is already elsewhere, gone on his own sometime in the last days. He glided so delicately out, his absence so continuous with his presence, with us and without us, that I didn't catch the moment and immediately it happened it had already gone and was behind me. So. Just me...

Stay, stay awhile, I whisper to the bed...

I want this death to happen because it is the end and I will finally rest. I don't want it to happen because it is the beginning and I will finally understand. We are together on the bed. It is familiar. Like how we were.

How precious, I tell him, we are here and I am seeing you off. I am sending you. My hand is in his hand. Go. I hum something, not anything. Go. I speak words, not anything. Go. I am not anything. Go. I am. (Coutts, 2014: 289–91)

Both of the partner extracts, Sandy's and Marion's, describe life continuing, being lived as full as it could be in the circumstances. In practice, the dying person remains in their chosen place, their home or hospice home "This is a place he can die well with us around him. Suddenly, overnight, we are home" (Coutts, 2014: 265). In both partner accounts there is a steady stream of visitors: friends, family, colleagues, for Barbara the rabbi, and for Tom and Marion, their three year old son. And there is open awareness of Barbara and Tom detaching, not always present to each occasion, drifting.

In both, albeit very different accounts, I sense much of my own experience of Jane's death. As partner/carer, even with the many forms and embodiments of support, an exhausted saturation point is reached. It is almost as if through the dying process the burden of the death act shifts from the dying person to their partner. One reaches their zenith with death and the other is released to a sorrowful nadir. Marion has it perfectly "I want this death to happen because it is the end and I will finally rest. I don't want it to happen because it is the beginning and I will finally understand" (Coutts, 2014: 290). Marion is with Tom as he dies but Sandy has been sent away for iced water by Barbara who dies before her return. I was asleep, lying beside Jane and believing the slightest movement or noise would wake me. Yet I felt ashamed, that I had failed

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<sup>70</sup> Tom Lubbock: 'a memoir of living with a brain tumour', *The Observer*, Sunday 7 November 2010. Available at: <http://www.theguardian.com/books/2010/nov/07/tom-lubbock-brain-tumour-language>

her in some way by being asleep. Equally, I had the feeling that it was her choice, as with Barbara, it was something private that she wanted without my gaze.

### **7.10 Summary**

This chapter first explored suffering as a feature of illness writing before reviewing the way stories of illness are told and the work that they do. This was framed in terms of Frank's (2013) illness narrative typology which was then compared with other similar constructs. Using these techniques enabled different aspects of the Dance to Death from Part Two, to be drawn out such as the interplay between living and dying. The chapter concluded with a comparison of co-created accounts of illness and dying to identify commonalities between them, and the illness narrative here.

## 8 Homecoming

### 8.1 *Introduction*

This chapter returns to the nature of aesthetic experience, first as a facet of nursing practice and then as expressed through the philosophical work of Schiller and Goethe's scientific studies. The earlier discussion from Section 2.3 on the relevance of German Idealism and the nature of aesthetic experience is further developed. A connection is made to Simmel's notion of sociability and Turner's interpretation of *communitas*. This leads to a discussion on the conceptualisation of place and its relationship to the Heideggerian notions of dwelling and homelikeness in the context of dying. The chapter concludes with a definition of aesthetic experience in the context of those who are dying.

### 8.2 *The Art of Nursing*

In my efforts to understand my experience of Jane's illness and death, I first rejected the former nurse within me. Yet in this thesis there are references to my experience as a nurse and of training to become a nurse. It has taken these years of intense study and my love-hate relationship with nursing, to appreciate what being a nurse now means to me. Becoming a nurse was a rite of passage between the familiar, secular world of London in the mid 1970s and the sacred world of healing as practised in a major Scottish teaching hospital. The experience featured all three of van Gennep's (1960) phases or rites: separation, transition and incorporation. I was separated from my home, my family and my freedom by the requirement to live in the probationer nurses' home for the first six months of training. It was as if I had entered a religious order with its rules, regulations and uniform dress. It took three years to complete the transition from gauche novice to independent practitioner. This was an apprentice system where we learnt by imitation and knowledge acquisition (Carper, 1978) knowing not to question what we saw or were told. Obedience was necessary for organisational control (Fisher & Freshwater, 2014) both in the school of nursing and the hospital. Once qualified, we became 'staff nurses' and were reincorporated in the secular world where the ill needed our care with its special skills and knowledge. Yet this was a time of transition for nursing as a profession although what was being incorporated was more concerned with the secular than the sacred.

There is neither time nor space to enter into a detailed explanation of the professionalisation of nursing over the past forty years. However, it is worth noting I had no sooner qualified when everything I held sacred about nursing was overturned by the demand for a scientific basis to its

nature and management (Allen & Lynne, 2006). Florence Nightingale described nursing as an art that was mostly concerned with cleanliness and practical common sense, typically the work of women. Children grow up with the hand of their mother cooling their fevered brow or salving their scuffed knees. A strong sense of the caring mother figure is nursing's companion story. I had the added bonus of exciting stories from my mother of the hospital ward featuring glamorous nurses and amorous male doctors. While she portrayed a romanticised view of caring work it nevertheless held certain attractions, sounding both scary and exciting. She omitted to tell me the reality of what blood and gore really smell like but her message was clear. I needed to earn my living, I was not bright enough to be a doctor but nursing was a good alternative. It was only much later that I realised she was legitimating her own life choices. From an early age, I had been trained in the traditional art of nursing, the laying on of hands and caring for the sick. I graduated from plastic dolls to my younger siblings as I crafted my art. My childhood reading from my mother's collection was Pugh's 'Practical Nursing' (1944) which details the qualities of a good nurse:

To become a good nurse, a woman must possess intelligence, a good education, healthy physique, good manners, an even temper, a sympathetic temperament, and deft clever hands. To these she must add habits of observation, punctuality, obedience, cleanliness, a sense of proportion, and a capacity for and habit of accurate statement. Training can only strengthen these qualities and habits; it cannot produce them. (Pugh, 1944: 3)

Feminists may well pale at this specification, more so when they learn that it is unchanged from the original version of the text written by a physician and a matron from St Bartholomew's Hospital, London (Stewart & Cuff, 1899). The definition persisted unchanged to its final edition (Pugh, 1969). It depicts the archetypal nurse, unintentionally romanticised, instantly recognisable and symbolic of the reassuring care that a sick person might wish for themselves. There is an implied maturity to this prototype nurse. She is not a girl who will become a woman through her training, she arrives as a woman already educated and demure. To this I aspired; I could become this person if I successfully completed the rites of passage that constituted nurse training in the 1970s. What we learnt was procedural, task-oriented, a system of techniques that could be performed in many settings, not just in hospitals. It was practiced on passive patients in the role of obedient recipients of these administrations. I was taught not to care as such but to give comfort by ensuring sheets were straight and crumb-free, pillows were plumped and artfully arranged, all seasoned with a light peppering of reassuring prattle. This was the art and craft of

nursing. It follows that if nursing is considered to be an art there must be a connection with aesthetics but not necessarily as a philosophy of the beautiful.

### 8.3 *The Aesthetics of Nursing*

As previously stated, I do not intend to provide an overview or an analysis of the evolutionary development of nursing over the last forty years save one aspect: the tension between nursing as an art and as a science. In an attempt to clarify and give value to the softer, less definable and evidential aspects of nursing, Carper proposed a model of nursing knowledge, derived from her doctoral research (Carper, 1975), that recognised the scientific aspects of nursing as ‘empirics’ and the art of nursing as ‘esthetics’<sup>71</sup> (Carper, 1978). The model is presented as four patterns of ‘knowing’ with the addition of personal knowledge in nursing and ethics as a moral component. In questioning the traditional, task-oriented and fragmented approach, an alternative, aesthetic pattern of nursing is proposed where “One gains knowledge of another person’s singular, particular, felt experience through empathic acquaintance” (Carper, 1978: 17). This configuration centres on the relationship between the patient as an individual, and the nurse with a repertoire of special skills or aesthetic knowing based on the particular, not the universal.

Carper’s model stimulated much subsequent research into the theory and practice of nursing (for comprehensive appraisal see Wainwright, 2000 and Zander, 2007). The model was amplified first by Munhall (1993) to include the pattern of ‘unknowing’ and then by White (1995) to include a socio-political dimension. Heath (1998) proposed the model be revised to include these additional dimensions. Curiously, no further work seems to have been done with or on the model by its originator, Barbara Carper, but the published version (Carper, 1978) has appeared in *Philosophical and Theoretical Perspectives for Advanced Nursing Practice* since its first edition (Kenney, 1996) and features in the most recent (Cody, 2014). The most consistent use of Carper’s model has been to provide methods for each pattern as practical exemplars in a text which has also evolved through many editions (Chinn & Kramer, 1994, 2014). The attributes of a nurse are now rather different:

When you, being the best nurse you can be, act so that emancipatory knowing, ethics, aesthetics, personal knowing, and empirics come together as a whole, your purposes for developing knowledge and your actions based on that knowledge become more responsible and humane and create liberating choices. (Chinn & Kramer, 2010: p19)

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<sup>71</sup> As an American author Carper uses this spelling throughout but I will use the more widely accepted ‘aesthetics’.



This quotation takes Carper's four elements and expands them to include emancipatory knowing, which is essentially the recognition of the situational socio-political context (White, 1995). This fifth pattern functions as a process by embracing the other four through reflective practice in a spirit of social justice. Chinn and Kramer (2010) contend that aesthetic expression is the most important aspect of emancipatory knowledge and action, as it presents an opportunity for transformative experience. In practice this would be demonstrated by a nurse who helps to alleviate suffering through novel and innovative means; in common parlance, thinking and working outside the box. However, conceptualising nursing as an art and worse, conflating art with aesthetics, is a contentious issue in the literature (Edwards, 1998; Raeve, 1998; Wainwright, 2000). While Carper's contribution to the development of nursing philosophy is appreciated, it is also criticised for its weak interpretation of aesthetic knowing (Boykin et al, 1994). The historical and philosophical basis for nursing to be considered an art form has been systematically reviewed (Johnson, 1994) but found to be in need of further work. This challenge has been taken up particularly by Wainwright who argues that the whole of nursing and not just aspects of it should be viewed as an art (Wainwright, 1999). With regard to aesthetics he contends "nursing is not a fine art, but that it is a fit object of aesthetic appreciation and that such appreciation is not only possible, but is also worthwhile" (Wainwright, 2000: 755). More recently "the lack of recognition of the difference between aesthetics and practice has resulted in a degree of conceptual incoherence in the nursing literature" (Archibald, 2012: 180) and has rekindled the love/hate dichotomous veneration of Carper's work.

The arguments against nursing as an art form are as much to do with the concern for scientific rationality and recognition of nursing as a human science (Derbyshire, 1999) as they are concerned with aesthetic appreciation. The overtly feminist language used by some authors (Chinn, 1994; Chinn & Kramer, 2011) combined with a clearly arts-informed narrative as used, for example, by Gaydos (2006) may have undermined the essence of the argument. Examples of simple actions such as a nurse placing her hand on an anxious person's shoulder as reassurance (Chinn & Kramer, 2011), spending time with a patient (Gaydos, 2006) or creating a social space for an illness story to be told (Leight, 2002) may support the claim of an aesthetic quality to nursing. However, these examples could also be interpreted as empathic, "the capacity for participating in or vicariously experiencing another's feelings" (Carper, 1978: 17) which she contends is an important aspect of the aesthetic pattern of knowing in nursing. This point

connects with that earlier from Frank (2013) on the reciprocity of empathy.<sup>72</sup> In a comparison between the writings of Florence Nightingale and Carper's model (Clements & Averill, 2006) there is evidence of the empathic role of the nurse:

Nightingale clearly discussed the necessary *presence* of the nurse with the client, as well as interpersonal interface and communication, as a pathway to knowing. She validated that knowing about the client is experiential, as well as shared. In essence, for a nurse to be empathetic toward a client, she or he must be fully present, at that moment, sharing the experience and what it means to both the nurse and the client at the time. Aesthetic knowing is clearly bound by consciousness, proximity, and human interchange at various levels. (Clements & Averill, 2006: 270, original emphasis)

The challenge in nursing and therefore for nurses, has always been to help the sick to feel better, to provide comfort and through compassion, to alleviate their suffering (Bouchal, 2007). The ability to give this care is both inherent, as a basic genderless, human response and in the skills taught. The nursing profession has striven to make the necessary knowledge and expertise explicit, changing nurse education from the apprenticeship model of accepted practice to an academic discipline founded on research evidence. My fascination with the difference between nurses as they perform their daily customs and rituals was rekindled when Jane was ill. I had a front row seat in the chemo unit or the day ward. Why did Jane, and by extension I, prefer some nurses more than others? Was it just personality or was there something more to the nature of their performance and was this somehow aesthetic? In simple terms, some nurses were easier than others, made more time for reassuring chat or were highly efficient in their work. Perhaps this can be explained thus "With aesthetic knowledge, the nurse expresses the artistic nature of nursing care by appreciating the act of caring for individuals." (Siles-Gonzalez & Solano-Ruiz, 2015: 5). The implication is that some nurses are more in touch or comfortable with their own feelings when caring for others.

When practising as a nurse, I generally felt uncomfortable with myself and certainly was not in touch with my feelings. I often felt powerless in the presence of overwhelming trauma, illness and suffering. I could see how much hurt and pain there was but beyond doing what was expected of me as a nurse, I could not engage empathetically with the patient. On occasion, this failing was perceived by more senior nurses who questioned my ability to care and to be a competent nurse. Part of my earlier interest in nursing research was to try and understand what

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<sup>72</sup> See Section 7.6

constituted this aspect of nursing that I failed to understand. I avoided nursing contexts that would require longer relationships with patients, preferring accident and emergency or the operating theatre. When I did become a charge nurse in an acute medical ward where patient stays were longer, I could distance myself from close contact through my managerial role. When Jane was ill, I was trapped in close proximity to someone who needed my care. Although much of the time during the Illness Period I was busy *doing* all aspects of running the household and caring for Jane, I came to realise that *being* near was what I had hitherto failed to understand.

The intentional doing for and being with another who is in need, is a facet of a transpersonal caring relationship, a core concept in Watson's (2008) theory of human caring science. The concept has an inherent moral commitment to protect and enhance human dignity. Other facets of this core relationship include love, mind-body wholeness and authentic presence. More recently this tradition has been taken forward in the work of Kate Galvin and Les Todres. They propose the knowledge domains of "head, hand and heart" (Galvin & Todres, 2007: 32) should be integrated with ethics and action into caring practice. They conclude with the observation that "the humming integration of head, hand and heart that naturally occurs becomes easily obscured by the excessive compartmentalisation of attention to specialized tasks" (Galvin & Todres, 2007: 42). But as a nurse, I had not recognised the 'humming' in my head for what it was. At the centre of Watson's model is the quality of the relationship between two people: the nurse and the patient. Does the nurse view patients as "objects to be manipulated and treated, or as human beings to be understood and cared for" (Halldorsdottir, 2008: 649)? Even in the era that I trained, metonymic descriptions for a young, male patient as 'the appendix in room three', were frowned upon despite its common practice. It was easier to 'care' for objects that needed doing for than people who needed being with, a failure to integrate service action with epistemology and ontology (Galvin & Todres, 2007).

#### **8.4    *The Nature of Aesthetic Experience***

Having explored aspects of the aesthetic aspects of nursing practice, I now want to consider the nature of aesthetic experience, initially from the perspective of someone who is dying. Jane realised that "you will lose your hair" (Blog post, Silver Linings, day 45) and the transformation by the disease of her lathesome body into a bloated caricature was an intense suffering for both of us. How might any of this be remotely concerned with aesthetics, the appreciation of the beautiful? I will argue that it is in the stark reality of facing death that a perceptual clarity

emerges enabling the transcendence of the phenomenal to the noumenal.<sup>73</sup> Sensations are heightened as their experience returns to the intellect in a process of enhancement and mediation. Explanations of aesthetic experience are invariably traced back to Kant despite the fact that his definition of the pleasurable observation of an object was by implication “the type of experience we have of those objects which we declare beautiful, and on which experiences our particular judgments of taste can be founded” (Neville, 1974: 193). A more recent sociological interpretation of Kant suggests that the aesthetic experience of cultural objects is characterised by the “free play of cognitive and numinous experience unstructured by concepts” (Battani, 2011: 1) and that “the form of the experience is dictated as much by cognitive structure as it is by social structure” (Battani, 2011: 12). Similarly, and in relation to arts-based research, the impediment to the Kantian interpretation of aesthetic experience which confines it to fine art is challenged (Jagodzinski & Wallin, 2013). Nevertheless, the emphasis continues to be in relation to the making and perception of art and its objects. A more spiritual view takes into account both the mystical aspects of the aesthetic alluded to by the philosopher William James and the relevance of nature, concluding with the suggestion that the varieties of aesthetic experience act as a gateway to “cosmic consciousness” (Jones, 2014). Yet aesthetic experience has an embodied and therefore phenomenological dimension to its cognitive perception (Joy & Sherry, 2003; Carel, 2011).

The complex nature and difficulty in determining a precise, contemporary definition for aesthetic experience<sup>74</sup> now questions its value and existence (Tomlin, 2010). Generally, it is described as an engagement with art or nature as a deeply moving piece of music, an exquisite painting or a beautiful landscape. In this sense, aesthetic experience “is precious and of fundamental value to human beings” (Tomlin, 2010: 1). In a collection of essays (Shusterman & Tomlin, 2010) resulting from a conference on the value of aesthetic experience, there is no unified definition but a range of interpretations. Renewed consideration of aesthetic experience could have the “potential to positively transform oneself, our fellow sentient beings and our environment” (Tomlin, 2010: 11). Again, exigency here negates a detailed appraisal of the arguments but Shusterman’s contribution to the debate, particularly his examination of the end of aesthetic experience (Shusterman, 1997; 2006) and his concept of somaesthetics (Shusterman, 1999; 2011), are noteworthy. Briefly, Shusterman argues that the decline of aesthetic experience in terms of its philosophical Anglo-American traditions has resulted from the emergence of

<sup>73</sup> Here my thinking is in a sense similar to Gendlin’s (2004) idea of coming into words, see Section 3.6.

<sup>74</sup> See Section 2.3.3 for an earlier definition derived from Schiller.

theoretical tensions between four definitional dimensions: evaluative, phenomenological, semantic and demarcational (Shusterman, 1997: 30). Viewed in this way aesthetic experience is valuable and enjoyable, vividly felt, meaningful and generally distinctive as art. He summarises his claim as:

[the] essentially evaluative, phenomenological, and transformational notion of aesthetic experience has been gradually replaced by a purely descriptive, semantic one whose chief purpose is to explain and this supports the established demarcation of art from other domains (Shusterman, 1997: 32)

In asserting that the body has a complex role in aesthetic experience, the notion of somaesthetics has been proposed as “essentially concerned with human flourishing by focusing on improving the use of one’s embodied self and one’s somatic experience” (Shusterman, 2011: 323). The concept was derived both from Shusterman’s own work in aesthetics and his embrace of eastern esoteric traditions. The term soma in this context is concerned with the inner or felt experience of the body and not its outward appearance (Arnold, 2005). Dance exemplifies somaesthetics where the soma is conceived in “the form of its physical skills, senses and pleasures plays no less a part in the living of a full life than conceptual understanding and the imaginative use of language” (Arnold, 2005: 48). To summarise, the phenomenological nature of aesthetic experience implies a sensate focus on an object as an experience felt in a particular way. If aesthetic experience is about something, it must have some dimension of meaning (Shusterman, 2006). In an echo of Heidegger’s (1977) concern regarding purely instrumental definitions of technology that disregard its essence, Shusterman argues that the value of aesthetic experience is all but lost to information technology as our “affective capacities wear thin” (Shusterman, 1997: 39). Then he reminds us of the “illustrious tradition of exploring aesthetics as a key to ethics and the art of living” (Shusterman, 1999: 308) which he finds exemplified in Schiller’s *Aesthetic Letters*, to which I will now return.

## 8.5 Schiller’s *Aesthetic Education*

In Section 2.3.3, I described the context and essential argument of Schiller’s *Aesthetic Letters* and their precursor, the *Kallias Letters*. For this study, there are two essential points to highlight from the latter, firstly “To interpret Schiller properly requires us both to recognize the distinction of meanings and to hold them at the same time together in a reciprocally illuminating unity.” (Schindler, 2008: 89). This requires appreciation of the word *form* or *Gestalt* which encompasses an understanding of not just the inner idea of something as matter, concretion, and organisation

as a whole but also its outward appearance. In this respect, Goethe's influence on Schiller is acknowledged (Schindler, 2008; Bishop, 2008); but *form* in the context of aesthetics, should always be prefixed by 'living'<sup>75</sup>. The complex metaphysical point being made is that *form* offers a semblance of life but it also articulates life as felt. It was this *felt life* that both Goethe and Schiller found to be true of all art. To further explain the point, something can be recognised as being beautiful without being first understood but then as understanding develops, appreciation deepens. This is "the 'both/and' character of form" (Schindler, 2008: 90) as presented by Schiller. The second relevant point from the *Kallias Letters*, concerns Schiller's interpretation of freedom as an intuitive action devoid of ulterior motive:

An action is morally beautiful, then, if on the one hand it is the fulfilment of a duty that is 'imposed,' so to speak, as an absolute necessity, and, on the other hand, it occurs as if it springs directly from the inner being of the agent as a wholly spontaneous act. That is to say, it comes simultaneously from without and from within. (Schindler, 2008: 93)

This is not simply the mechanistic performance of a task but an action that arises spontaneously from an inner sense of moral duty and technical ability. On this basis, I suggest that with regard to nursing, a nurse may act routinely and quite correctly but perhaps lacks a sense of what might be described as 'nurseness' or even 'carerness'. This means a nurse with an inner sense of Schillerian freedom acts intuitively, as if without conscious thought, and is therefore more 'physically present' (Schindler, 2008: 92). In turn, this speaks to the presence of the nurse as an aesthetic knowledge that is "clearly bound by consciousness, proximity, and human interchange at various levels" (Clements & Averill, 2006: 270). I had a sense of this, as an inner knowing, when caring for Jane, a feeling that had alluded me when I worked as a nurse. This might also be interpreted as my recognition of how "empathic imagination is a central faculty for integrating the head, hand and heart" (Galvin & Todres, 2007: 42).

The justification for this detailed yet cursory attention to Schiller's interpretation of aesthetics is twofold. First, although I know Jane understood these subtle dualisms in a particular way, I cannot provide much in the way of actual evidence beyond citing her work written twenty years previously. I realised that I had noticed something subtle in her demeanour during her illness. This was not written in her blog or other writings but there was something in the way she carried herself, an almost tragic serenity. At the time, this was generally perceived by friends and family as courage, stoicism and bravery. While these characteristics were true, what I saw was her

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<sup>75</sup> WW: 310

physical suffering counter-balanced by a sense of inner calm. This is the dance between outer discomfort and inner peace, between seeing me as her healthy, living partner while she herself is dying. She knew, from her studies of both Schiller and Goethe, that this was unity, a holistic way of being. My argument is that the phenomena of her illness and the noumenal rationalisation of her prognosis was transcended through aesthetic experience. That said, I am also acutely aware that a further claim is being made which is that the methodological process of Jane's doctoral work led to a personal transformation of her own beliefs. Having said I have little evidence to support these claims, after some further explication of Schiller and Goethe, I will provide some illustrations from the material gathered in the course of this study, to support my case.

The *Aesthetic Letters* were introduced in Section 1.4 as the core methodological text for Jane's doctoral studies and as part of the intellectual bond between us. I have her well annotated copy and her interest is evidenced by both the pencil annotations and subsequent works (Plenderleith, 1991; 1993). The complex language game employed by Schiller in the text combined tautology to deflect attention away from the concepts. Antithesis is used to create tension, and occasionally chiasmus where the second term is inverted (Schiller et al, 1967). An example of this complicated structure appears in a footnote to *Letter XIII*, "Both principles are, therefore, at once subordinated to each other and co-ordinated with each other, that is to say, they stand in reciprocal relation to one another; without form no matter, and without matter no form"<sup>76</sup>. The chiasmus comes at the end when *form* and *matter* are switched.

In the text, Jane has underlined the description of the structure "antithesis and chiasmus combine to bring to birth in language, as it were, that 'third thing', the play-drive, which is to be brought to birth in reality through the complex interaction of the two fundamental, and opposed, drives of the psyche"<sup>77</sup>. An obvious question is why Schiller would apparently complicate an already complex argument by intertwining word pairs. The explanation is that his solution to the difficulties of the human condition does not require any new faculty of human nature, but on better use of those already possessed "by raising, now the one, now the other, antithesis to synthesis he can express his belief that the return is in reality a progress"<sup>78</sup>. Jane has not just neatly underlined this quotation in pencil but also added 'NB' in the margin. The term "binary synthesis"<sup>79</sup> finally appears in an appendix, as the particular type of synthesis used to

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76 WW: 85

77 WW: lxx

78 WW: lxxxvi

79 WW: 350

describe the raising of one polarised term to a higher concept and depicted as a movement from the base to the apex of a triangle (see *Appendix 2: Binary Synthesis*). The authors comment that this is of the same type as used by Goethe and was what Jane meant by her expression ‘return enhanced’.

Binary synthesis figures later in the *Aesthetic Letters* as a dance metaphor illustrated by the co-ordinated movements of a group of dancers. The description of the interplay between word pairs is appealing, “figures are executed, now by the whole *ensemble*, now by a single pair”<sup>80</sup>. Schiller liked to keep the mind moving and not fixed in his discussion of difficult ideas (Shaw, 1986). The final point I want to draw from Jane’s annotations is prescient, “life and death, stasis and process, death as renewal, the relation of art to all of these”<sup>81</sup>. Schiller’s concept of play as an emergent property of man’s two basic drives, one of experience or content, the other of the rationalisation of content through reason, is relevant in a particular sense to this study. The object of the play-drive is, according to Schiller, “living form [which is] a concept [that has] all the aesthetic qualities of phenomena ... what in the wildest sense [would be termed] beauty”<sup>82</sup>. A more recent interpretation of Schiller’s concept of aesthetic play is as “the contemplation of the beautiful; it is there that man truly plays, and where man truly plays, where he is satisfying no material need nor fulfilling any purposes, he achieves a temporary reunion of the two sides of his nature” (Sharpe, 1991: 158). The psychiatrist Susan Bentley, who has a particular interest in Schiller’s concept of play, suggests pleasure in this sense could be viewed as a product of the German aesthetic tradition “a valuable, life-giving source of well-being” (Bentley, 2009: 307). Pleasure arises then from the interplay between the sensory perception of an object and the cognitive recollections or memories associated with previous experiences. This interpretation is both a return enhanced and cognate with Shusterman’s (1997) account of aesthetic experience.

It could be argued that this sense of an aesthetic emanating from the drives is abstract, has no practical purpose, and could only be enjoyed by an idealised concept of the person. However, in the context of Schiller’s earlier essay *On Grace and Dignity*, this ideal person is a refinement of his beautiful soul that has a “sense of lightness or ease because it is free from the constraints of both sensibility and reason” (Beiser, 2005: 141). Schiller’s intended meaning is that “A beautiful soul spreads an irresistible grace over a physique lacking in architectonic<sup>83</sup> beauty and often one even sees it triumph over natural shortcomings” (Curran, 2005b: 153). To me this serves as an

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81 WW: lxxxix

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accurate description for Jane's physical disfigurement as a result of her illness being overcome by her graceful comportment.

In the context of living with life-limiting illness pleasurable feelings resulting from an aesthetic experience have the potential to transcend, "Even momentary wholeness gives us renewed reserves of psychic energy with which to meet the moral challenges of our lives and a refined sensibility to apply in our dealings with the world." (Sharpe, 1991: 160). A simple example from Jane illustrates this point "I think I sometimes see things more intensely now – I thought eiders were black and white birds, I'd never really noticed that they have pinkish chests, and the most beautiful blue-green hue to their cheeks" (Blog post 'Catching up: Plants, Gardens, Cars and Other Things', day 291). Similarly, the playwright Dennis Potter describes the plum tree he can see from his window as he writes "I see it is the whitest, frothiest, blossomest blossom that there ever could be" (Bragg, 2007). Viktor Frankl in his memoir of concentration camp survival, recalls a dying woman being sustained by the view from her window where "she could see just one branch of a chestnut tree, and on the branch were two blossoms ... [she talked to the tree and the tree replied] 'I am here – I am here – I am life, eternal life'" (Frankl, 2004: 78). All three accounts are recollections of seeing the dynamic nature of life and not the static artifice of the arts.

## 8.6 Goethe's Scientific Studies

A connection can be made from aesthetic experience and its relationship to binary synthesis through Goethe's scientific philosophy to phenomenology. For Goethe aesthetic experience is: "the indirect way by means of which ("subjective") Idea and ("objective") Experience converge" (Stephenson, 2005: 567, original capitalisation). This interpretation is cognate with the ideas Schiller develops in *Aesthetic Letters VI to XXII*:

Goethe, like Schiller, distinguished not only between different modalities of the imagination, but also between those of aesthetic experience. The aesthetic also operates in three different modalities: there is the "subordinate" role that Schiller envisages for the aesthetic as the prime matter, as it were, on which the intellect goes to work in order to produce concepts and theory; there is the "co-ordinate" role as direct object of enjoyment; and there is its "super-ordinate" role in gracious living (Stephenson, 2005: 567 fn5)

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83 Architectonic in this sense does not refer to architecture as such but to the more metaphorical understanding of the systematic arrangement of knowledge based in nature and not thought itself (SOED, 2007).

For example, if I look at a red rose growing in my garden I see it as a direct object subordinated through the conceptual lens of botanical art (in which I have some training) and experience a certain pleasure in the rose's appearance. The aesthetic deepens as I see the rose's red colour as an outward expression of its internal meaning or redness (Schindler, 2008). It is in this fundamental interplay that we sense the rhythmic patterns of the real world as "tension, intensity, and resolution" (Stephenson, 2005: 568). Furthermore:

Thinking and doing, breathing in and breathing out, moving backwards and moving forwards, question and answer: pairs of opposites which make sense only in relation to one another, which function fully only in coordination ... Binary synthesis is descriptive of the process of existence rather than prescriptive of the process of logic. The oppositions in a binary synthesis function truly only together, but they remain distinct: either or both of the fundamental polarities appears enhanced through reciprocal, subordinating interaction with the other. (Plenderleith, 1993: 298)

And it is Jane's own words that there is a sense of the natural rhythm of life, the ebb and flow of living and dying. The red rose will wilt, shedding its petals on the ground where they will gradually decompose and feed the bush itself. For all their complex abstractions, both Schiller and Goethe are describing natural processes of life, complete with an asymmetrical co-ordination of opposites. For, in Goethe's world "there are no perfect Forms; only beautifully-formed imperfections" (Stephenson, 2005: 569). I believe it was in this sense of nature's beautiful imperfections that Jane understood her cancer "My body has done this to itself" (Blog post, A different mindset, day 98). In the course of this study I discovered a connection between Goethean science and human geography that informs the understanding of place (Seamon, 1979; Brook, 1998; Cameron, 2005). This links to the earlier finding<sup>84</sup> regarding the embodied feeling of being at home and unhomelikeness (Svenaeus, 2003).

## 8.7 *Being in a Human World*

The link between Goethe's scientific writing and interpretations of place is through phenomenology to humanistic geography, a discipline that has a particular interest in a different way of looking at the human inhabited world (Seamon, 1979). Although Goethe's interest was in the experiential study of phenomena as they appear in nature, the philosophical discipline of *phenomenology* did not emerge until the twentieth century with the conceptual language of Edmund Husserl (Seamon, 1998). His purpose in developing phenomenology was to find a

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84 See Section 4.2

method for investigating the lifeworld which “places the problematic of human consciousness and its world-constitution at the center of phenomenological inquiry” (Simms, 2005: 171). Unsurprisingly, phenomenology has become a significant approach in the study of human experience in health and illness, particularly nursing (Dowling, 2007) and includes iterations through such luminaries as Heidegger, Merleau-Ponty and Gadamer, (Wojnar & Swanson, 2007).

The particular aspect of humanistic geography that relates to this study is the relationship people have with the places in their lifeworld, defined as “the culturally defined spatiotemporal setting or horizon of everyday life” (Buttimer, 1976: 277). While many factors may disrupt our relationship with particular locations such as home or work place, ill health can be an additional existential disturbance to spatial life. There is more recent research into the relationship of the lifeworld to caring and well-being (Galvin & Todres, 2012), to which I will return but for now I want to continue with an earlier perspective that facilitates a connection between Goethean insights and more recent theories. In a 1970s study (Seamon, 1979), a group inquiry approach was used to explore the lifeworld as the assumed “pattern and context of everyday life through which the person routinely conducts his day-to-day existence without having to make it an object of conscious attention” (Seamon, 1979: 22). The relevant findings are threefold: a definition of ‘at-homeness’; the concept of ‘place ballet’; and a triadic model of environmental experience.

Three primary themes of movement, rest and encounter were used to guide the inquiry and reveal the whole. Movement is a long-standing theme for geographers, defined as “any spatial displacement of the body or bodily parts initiated by the person” (Seamon, 1979: 33). Clearly this can range from raising an arm to reach something on a shelf to walking briskly up a hill. Movement is not confined by place but it does have a temporal dimension. ‘Body ballet’ is a term used to describe purposeful action as “a set of integrated gestures and movements which sustain a particular task or aim” (Seamon, 1979: 54) such as washing, cooking or knitting. As these co-ordinated movements generally form habitual routines in space and time, they are termed “place ballets” (Seamon, 1979: 56). The movements are choreographed and performed by the person as they negotiate their way through the places and routines of daily life. The familiarity of this dance changes as new places require accommodation; this can be both exhilarating and challenging. On occasion the bustle of street life may appear attractive after a period of isolation but the sterile uniformity of a busy hospital corridor may arouse feelings of

*dis-ease*. The latter can be understood as ‘placelessness’ which describes both “an environment without significant places and the underlying attitude which does not acknowledge significance in places” (Relph, 1976: 143).

Hospitals can cause a sense of placelessness for their patients. Even when some personal ephemera are permitted, the actual bed space occupied may be frequently changed by service pressures. A precious view from a window may be lost when a bed is turned to face another direction; a preferred seat in a day care unit may not be available. These may seem trivial, incidental examples but I suggest that the experiential significance of place in health care environments is poorly understood and generally ignored for expediency. The discussion of place would be incomplete without attention to the place most people feel at ease, their home. In earlier chapters I have raised the sense of displacement and discomfort that can arise from not feeling ‘at-home’. In a broader sense, this is both a place of rest and can refer to “any situation in which the person or an object with which he or she has contact is relatively fixed in place and space for a longer or shorter period of time” (Seamon, 1979: 69). So it could be, for example, a place of work, medical treatment or even a café. However, it is the dwelling place or home that is the spatial centre of ‘at-homeness’:

the usually unnoticed, taken-for-granted situation of being comfortable in and familiar with the everyday world in which one lives and outside of which one is ‘visiting’, ‘in transit’, ‘not at home’, ‘out of place’ or ‘travelling’ (Seamon, 1979: 70)

Here there is no need for place ballet, formality or presentation of self (Goffman, 1971). At-homeness is manifest in feelings of rootedness, appropriation, regeneration, at-easeness and warmth (Seamon, 1979: 87). In addition to these aspects, the sense of at-homeness is further enhanced by Heidegger’s notion of dwelling in the sense of sparing and preserving (Seamon, 1979: 92). Environmental awareness is an indicator of this where dwelling with a care-taking role finds “the free sphere that safeguards each thing in its essence” (Heidegger, 1993: 351). Seamon argues for attention to these concepts in relation to the physical design of places, suggesting that place ballet enhances the sense of rootedness participants have with their environment. It also in effect assigns particular roles to specific areas thereby reinforcing familiarity and trust. In turn a sense of ease and even warmth is evidenced which facilitates sociability as place ballet “fosters a sense of place which provides participants with spatial order

and identification as it protects them from the intrusion of uninvited people and events from the world at large” (Seamon, 1979: 95).

The final point to draw from this consideration of experiential environments is the nature of human interaction or encounter that occurs between movement and rest. Seamon (1979: 101) proposes a person-environment awareness continuum between two tendencies of mergence and separateness. At the *tendency towards mergence* end, the boundary between the world and the person is blurred as they become intensely aware of their environment; they are at one with their world. At the other end of the person-environment awareness continuum, is the *tendency towards separateness* where the person appears oblivious to the surrounding world; the person is looking inwardly. The ebb and flow of this awareness in the world “continually advances and retreats like the action of waves on shore” (Seamon, 1979: 103). Here there is almost a binary synthesis between the polarities of mergence and separateness, but the movement is back and forth. For Goethe, and indeed Schiller, there would be an enhancement of one by the other through the process of reciprocal subordination. For me, the introduction of intermediate stages disrupts the effect of the tension between mergence and separateness. It follows that an individual might have heightened awareness but feel quite alien to their surroundings, not at one with their world. For example a patient newly admitted to hospital and sitting bolt upright in bed, intensely aware of their surroundings yet appearing oblivious as they struggle to cope with the new environment. In this configuration, the continuum seems to fail; the patient is simultaneously at both ends. However, as a binary synthesis the reciprocal interplay between mergence and separateness should lead to the emergence of a steady state as the patient relaxes into their new situation and feels more at ease.

The subtle variations between the two poles are perhaps better exemplified as intermediate stages on the continuum, starting at the separateness end (Seamon, 1979: 104–111):

- obliviousness – conscious attention is turned inwardly to thoughts, feelings, imaginings, fantasies, worries or bodily states that have little to do with the world
- watching – a situation in which the person looks out attentively upon some aspect of the world for an extended period of time
- noticing – a sudden thing from which we were insulated a moment before flashes to our attention

- heightened contact – feeling a serenity of mood and vividness of presence; self awareness is heightened and simultaneously the external world seems more real

A more recent although not directly related work recognises that “Goethean research demonstrates that each living creature has a unique manner of presence in the world.” (Seamon, 2005: 98). As humans this presence is how we appear, behave, live and experience the world. Nevertheless, what Seamon describes as heightened contact is in fact an excellent foundational definition of aesthetic experience notwithstanding the earlier remarks regarding such definitions. In light of this, I suggest that in addition to the phenomenal and noumenal aspects of aesthetic experience, there is also context. This addition can then account for not having an aesthetic experience when someone alongside does, as in the case of personal preferences for art, music and vistas. Or in an embodied context between being well and being ill, particularly for those who are dying. It is in this context that I now define aesthetic experience as *feeling a serenity of mood, a vividness of presence and a heightened self awareness*. In short, a sense of oneness which is recognisable by its intensity and striking presence. I make no apology for using this again<sup>85</sup> “I think I sometimes see things more intensely now – I thought eiders were black and white birds, I’d never really noticed that they have pinkish chests, and the most beautiful blue-green hue to their cheeks” (Blog post ‘Catching up: Plants, Gardens, Cars and Other Things’, day 291). I remember the scene on the beach in North Berwick as the sun was setting and the eider ducks were coming home to settle for the night. There was an intensity to the light, it was on my birthday in February and their breeding plumage was indeed vivid. In that moment her dying and my living were irrelevant; we were both present watching the bobbing ducks with divine pleasure. Sometimes an aesthetic experience can be shared, especially in the context of two people who share a deep, emotional connection.

## 8.8 Sociability and Communitas

There is a further aspect of aesthetic experience to which I alluded at the start of this chapter regarding human companionship. It touches on the nature of the caring relationship in both an individual and a wider sense; as the interaction between a nurse and her patient or between the patient and her companions. The German sociologist Georg Simmel (1858–1918) had a lifelong interest in Kant and Goethe (Lee & Silver, 2013). Throughout his life he sought connections between sociology and aesthetics (Fuente, 2008) which he came to describe as sociability,<sup>86</sup> “the

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<sup>85</sup> See Section 8.5

<sup>86</sup> See Section 7.8

play-form of association [which] is related to the content-determined concreteness of association as art is related to reality” (Simmel, 1949: 255). The reciprocal and relational nature of the interaction is characterised by the principle that “the pleasure of the individual is always contingent upon the joy of others” (Simmel, 1949: 257). Others have noted the connection to Schiller’s aesthetics (Fuente, 2008; Lee & Silver, 2013) but not that the play-form is a drive “which presses toward this form of existence and often only later calls forth that objective content which carries the particular association along” (Simmel, 1949: 255). This could also be interpreted in Schiller’s terms of human drives where the play-form (play-drive) emerges through the association with existential form (form-drive) which is then organised by the ‘objective content’ (material-drive). In other words, there is “more to his account of the aesthetics of social life than the insight that form separates art, or for that matter any type of aesthetic experience, from the rest of life” (Fuente, 2008: 353).

In this context, the most relevant aspect of Simmel’s work which exemplifies the aesthetics of social life, is his sociability of the meal (Simmel, 1997). His argument starts from the premise that eating and drinking are the thing people have in common. From this he then draws his interpretation of the meal as a sociological matter that “arranges itself in a more aesthetic, stylized and supra-individually regulated form” (Simmel, 1997: 131). The meal is the basis for the convergence of aesthetic and social form through its processes of social bonding (Fuente, 2008). As an aesthetic experience eating is entirely individual, we cannot eat the same food but the same sounds and images can be enjoyed. For Simmel as a sociological structure it “attains a synthesis of individuality and commonality rare even among the cultivated arts” (Fuente, 2008: 358). It was this form of aesthetic experience that was the most powerful for Jane and she recounts many shared meals in the blog. Confidentiality negates much quotation but this extract is illustrative:

... a work colleague came for lunch. We had a lovely, warm, intimate and insightful conversation, touching on a wide variety of topics, from the state of technology-enhanced learning in UK higher education to body donation. As [he] said, no-one could accuse us of small talk. (Blog post ‘Friends and Family’, day 307)

While at this late stage in her illness, Jane was unable to actually eat much but she could fully participate in the conviviality. Furthermore:

The fact that we must eat is a fact of life situated so primitively and elementarily in the development of our life-values that it is unquestionably

shared by each individual with every other one. This is precisely what makes gathering together for a shared meal possible in the first place, and the transcendence of the mere naturalism of eating develops out of the socialization mediated in this way. (Simmel, 1997: 135)

However, Simmel gave his paper on the sociability of the meal, to the first meeting of the German Sociological Society in 1910, at a time which goes some way to explain his class bias “Compared with the image of someone eating in a farm house or at a workers’ festival, a dinner in educated circles appears to be completely schematized and regulated” (Simmel, 1997: 132). Nevertheless he uses the orderly principles of aesthetics to illustrate how behaviour during the meal is regulated as people take turn to serve themselves. Even when someone is dying, their participation in the very basic orderly structure of a shared meal acts as a balance to the otherwise disruptive chaos of their illness. Jane’s blog posts are punctuated with food enjoyed as is Coutts’ (2014) memoir of her dying husband with its frequent lists of food and appetising descriptions of food gifts. More poignant is the flask of special fish soup she brings her husband in the hospice “Talking to the chef I have the urge to tell him who the soup is for, as if to stress to him how much it means. But I don’t say anything ... I do the errand and hurry back. He eats three teaspoons before he stops” (Coutts, 2014: 284).

The importance of the meal in the context of the dying can be further emphasised by reading it as part of rite-of-passage ritual. Simmel contrasts world religions and “the cults of antiquity [who gather] together for the sacrificial meal” (Simmel, 1997: 130). For the dying person this may be an opportunity for what Victor Turner terms spontaneous *communitas*, a relationship that “appears to flourish best in spontaneously liminal situations – phases betwixt and between states where social-structural role-playing is dominant, and especially between status equals” (Turner, 1969: 138). Spontaneous *communitas* is akin to what hippies might have called “a happening” (Turner, 1969: 132) which could be described as the impromptu congregation of people to engage in the mutual appreciation of each others company. Following his death, Turner’s wife Edith continued to explore his ideas about ritual, rites of passage and his own term, *communitas*. She describes the connection he found “between the joy of *communitas* and rites of passage [as] moments of change freed from the structures of life” (Turner, 2012: 2). It can appear unexpectedly and it “often comes in the direst moments of the life of a person” (Turner, 2012: 2). In Jane’s liminal, threshold state between living and dying, and having asserted her right to die at home, it becomes a sacred place. Here she can continue to participate in the ritual of shared meals with friends and family. There may be exquisite moments of intersection and



alignment between the people attending, the sacred place of home and particular sensations: sights, sounds, smells, touches and tastes. These are the aesthetic experiences of dying, the mysterious, fleeting observations that those who are not *dying* might make:

This evening we have a little party. A small group come for wine and songs. Tom knows the friends who come this evening. To each one's touch and greeting he utters a different sound but his eyes are closed. Only when he hears the voice of Ev and his homecoming does he open them. I see this. I am the only one who does. I am so very lucky. I see that look. (Coutts, 2014: 284)

Intuitively we know those moments yet I doubt they can be collectively studied in any formal sense. While it is true that pleasure is not a necessary condition for aesthetic experience (Carroll, 2002), there may well be a bittersweet quality or an element of pathos to aesthetic experiences in the context of dying. But I contend that these are the precious moments in the memories of those who live on after the death of a loved one “[Jane's youngest sister] would come through in a heartbeat if I asked her to, but is busy with the hum of her life and anyway I agree with her that she'd prefer to remember me on the beach at St Andrews” (Blog post, ‘So Much Love’, day 330).

## 8.9 *Coming Home to Heidegger*

In this penultimate section, I want to explore how the sense of *at-homeness* was manifest for Jane. As her illness progressed, difficult symptoms like ascites appeared which necessitated further encounters with hospital services. During these physical separations from the place where Jane was most at ease, I tried to maintain vestiges of what I now understand to be a sense of at-homeness. It was the little things: bringing her food, a scented hanky and a small basket of essentials (tissues, lip salve, glasses, pen, notebook, a dog knitted by my sister). She liked her bed to be beside a window with a view or at least of somewhere else. So whether it was in the hospital or briefly in the hospice, she had the makings of home and a sense of well-being.

There is a strong connection between the work of Galvin and Todres on existential well-being in health care and Seamon's earlier work discussed in the previous section. They have developed a conceptual framework of well-being centred on the unity of dwelling-mobility (Todres & Galvin, 2010; Galvin & Todres, 2011). Their theory is derived from Heidegger's ontological conceptualisation of homecoming (Todres & Galvin, 2010) where dwelling-mobility “is both ‘the adventure’ of being called into existential possibilities as well as ‘the being at home with’

what has been given. It carries with it a sense of rootedness and flow, peace and possibility” (Galvin & Todres, 2011: 2). The authors acknowledge that while there are different interpretations of Heidegger, particularly as his work changed over time, they have found Mugerauer<sup>87</sup> (2008) to be both an accessible and consistent analysis. It is worth noting that as Heidegger was born in 1889 and died in 1976, his lifetime spanned one of the most simultaneously innovative and destructive periods in human history. The effect not least of the atomic age has been attributed in his later writing to his interest in technology (Mugerauer, 2008). Heidegger argued that our addiction to the ease and flexibility of technological devices would determine our experience of everything in terms of its ease and flexibility (Dreyfus, 2004). Heidegger is recognised as being difficult to understand and interpret not least because of his complicated use of language<sup>88</sup> (Dreyfus, 2004; Mugerauer, 2008). In his desire to break with philosophical traditions he was both provocative in style and had a preference for neologisms. Language games are not without precedent in this study as the earlier discussions<sup>89</sup> on aesthetic discourse have illustrated. Direct connections between Goethe and/or Schiller and Heidegger are not obvious. Links to Goethe’s colour theory and also to his conception of subject-object relations,<sup>90</sup> can be found in Heidegger’s essay on *Science and Reflection* (1977: 155). In this essay<sup>91</sup> and some of Heidegger’s other writing there does seem to be a certain similarity, possibly an interpellation, reminiscent of both binary synthesis and the Urphenomenon. In addition, like Schiller, Heidegger employed a threefold pattern to his work: though not confined to a single text, it extended across his entire corpus (Mugerauer, 2008). To investigate what it means to be human, the conventional approach would be to either focus on the subjective, internal dimensions of life or the objective, external world. Like Goethe, Heidegger rejected this divide and wanted a way to see the human being and the world, not as separate but together (Mugerauer, 2008).

In *Being and Time* (1996) the text for which Heidegger is best known, he embarks upon an ambitious project to discover the meaning of being (Dreyfus, 2004). In fact, the book is the groundwork for his subsequent theories spanning his lifetime. A novel interpretation of much of Heidegger’s corpus contends that his work is centred on the dynamic of “homelessness-

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87 It may be worth noting the connection with Seamon, see Seamon and Mugerauer (1985).

88 See also the translator’s preface to *Being and Time* (Heidegger, 1996).

89 See Section 2.3.4

90 Stephenson, 2005

91 First given as a lecture in 1954.

homecoming-home” (Mugerauer, 2008: 17). Holderlin’s poem, *Homecoming* (Heidegger, 2000) was particularly influential for Heidegger. He notes that at first the poem appears to be about a joyful return home but it is the last stanza that caught his attention where the word ‘care’, “suggests nothing of the joyful mood of someone who returns home care-free” (Heidegger, 2000: 32). Holderlin, who was a contemporary and acquaintance of both Goethe and Schiller, lays out in the poem an “ur-phenomenology of homecoming” (Mugerauer, 2008: 17). Through his comparative analysis of Heidegger and Holderlin’s poem, Mugerauer (2008: 17, my emphasis) has identified six phases to the phenomenon of homecoming:

1. initial being at *home* (even though not at home there)
2. *homelessness* or wandering in the foreign
3. turning towards home
4. a moment of *homecoming* or arrival
5. learning to become at home
6. abiding or dwelling near the primal source, the *home*

The binary synthesis then, is the return enhanced from wandering in foreign places to coming home, content to abide. Heidegger wrestles with the same dilemma as Goethe: how to re-present the complexities of primal phenomena in discursive language. For both, the solution is poetry where Goethe finds “The presence of the Urphenomenon must be felt in its representation. Poetry is a re-symbolization of a primary symbolic event” (Stephenson, 2005: 573). And Heidegger in his later work develops a deeper and “*originary manner of thinking and saying with which to recover ... the relationship of poetizing language and the world, and the focal phenomena of dwelling, region, building*” (Mugerauer, 2008: 11, original emphasis). Another way in which Heidegger practices his ‘originary manner of thinking’ is found in “meditative thinking [where there is] non-representational meanings that are thinking’s proper analogue to poetry and mysticism” (Mugerauer, 2008: 12). However, although we are all capable of this kind of thinking it lies dormant within us and needs to be awoken in order “to notice, to observe, to ponder, to awaken an awareness of what is actually taking place around us and in us” (Pezze, 2006: 100).

This thinking with heightened awareness and through poetry provides a connection to the kind of thinking necessary to appreciate and perceive the Urphenomenon. Schiller, in his *Aesthetic*

*Letters* had established a mode of thinking or aesthetic imagination where the “co-ordinations of the abstraction of understanding with what is presented to sense, as opposed to our ordinary, everyday, imaginative activity in which the latter is subordinated to the former” (Stephenson, 1983:162). The botanist, Agnes Arber whose interest in plant morphology and therefore some of Goethe’s scientific writings, interpreted his term *Anschauung* as one which combines “the immediacy of knowledge of, with the mediate character of the knowledge about, which is reached by the analysable processes of discursive thought” (Arber, 1950: 209). And when Wilkinson and Willoughby (Schiller et al, 1967) found the term to be untranslatable, they cited Arber. By way of clarification, Stephenson defines Goethe’s preferred term for the highest form of perception, the ‘pure phenomenon’ or *Anschauung*, as ‘aesthetic intuition’ which can be applied to any or all of “the instances of sensuous perception that occur within the open-ended, cyclical, process of ever more specific (and ever more theorized) insight” (Stephenson, 2005: 563).

Heidegger does make the occasional specific reference to the Urphenomenon<sup>92</sup> as, for example “Not-being-at-home must be conceived existentially and ontologically as the more primordial phenomenon” (1966: 177). But he frequently employs phenomenologically reduced terms (Sheehan, 2004) when, for example, he states “Being\* is the most ‘universal’ concept [Footnote: \*the being, beingness]” (Heidegger, 1966: 2). In other words meaning becomes ‘meaningfulness’, a technique that is cognate with the earlier explanation<sup>93</sup> of red and ‘redness’, which is Schiller’s both/and aesthetic form (Schindler, 2008). In phrases such as “Being is found in thatness and whatness, reality, the objective presence of things” (Heidegger, 1966: 5) what he is really trying to say, as he did in later work, is that it “is language that tells us about the essence of a thing” (Heidegger, 1993: 348). This claim is supported by the idea that category membership is a question of degree and not simply yes or no (Lakoff, 1973). For example in a “hierarchy of birdiness” (Lakoff, 1973: 459), a robin will have a higher position than a chicken or a bat. So birdiness is the extent to which the ‘bird’ matches its ideal type and in this sense can be interpreted in a manner similar to the Urphenomenon. What Heidegger seeks to achieve in what might be perceived as obfuscation, is the opposite. He wants to take us back to the earliest meaning of words which was why he was drawn to the poetry of Holderlin and also mixes accepted meanings with neologisms.

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92 In one of his last works, Heidegger (1973) makes direct reference to Goethe’s primal phenomenon in relation to space as an irreducible concept.

93 See Section 8.6

Of the many words with which he played, there are two that I wish to explore in a little more detail. Neither word has an analogous variant in English but approximations are given for each with references to fuller discussions. The first is *Gegnet* or ‘abiding expanse’ (Pezze, 2006) and the second is the previously mentioned<sup>94</sup> *Heimat* which is somewhere between home and homeland but means neither (Hammermeister, 2000). For Heidegger, *Heimat* includes both “a linguistic and a regional aspect that in turn are mediated in dialect” (Hammermeister, 2000: 314). In this sense, dialect acts as an echo to an earlier language now lost to mankind. In addition to the sense of landscape and language, in the poetry of Holderlin, there is both an “attempt to prepare for a reawakening sense of return to *Heimat*” (Hammermeister, 2000: 318). The idea of regionality is extended with *Gegnet*, an old form of the German word *Gegend* or region. Heidegger uses the older form to invoke a sense of “an enchanted region where everything belonging there returns to that in which it rests ... the region of all regions” (Pezze, 2006: 106). There is a sense of a hazy, distant horizon, somewhere in the future yet in full awareness of the past. This could also be understood as a return enhanced, not necessarily to a physical place but to the spirit of the sense evoked by remembering the place.

### 8.10 The Aesthetic Experience of Dying

I now want to briefly consider the aesthetic in relation to landscape. Extending the role of place in the lifeworld (Seamon, 1979) reveals it may also be a locale for aesthetic experience and as a place of healing, a therapeutic landscape (Gesler, 1992). However the therapeutic landscape is more “a geographic metaphor for aiding in the understanding of how the healing process works itself out in places” (Gesler, 1992: 743). Yet, using the already vague term landscape in this way is perhaps to ‘stretch’ (Brook, 2013) it too far. It is important to recognise that the concept of landscape needs to be understood as being ‘lived in’ and not simply ‘viewed’ (Brook, 2013: 109). While conventionally landscape may be romanticised as a picturesque vista, as an aesthetic experience it requires engagement through an embodied whole “the fact that the landscape speaks to all our senses, and particularly the kinaesthetic sense, means that just to view it would be not only to miss the richness of the landscape experience but also to fail to become part of that aesthetic field” (Brook, 2013: 113). In this sense, our interaction with landscape could be considered a somaesthetic experience.

Jane had a strong sense of being Scottish, of being from a particular place with a distinctive landscape and a language that is more than a dialect of English. Two examples serve to illustrate

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<sup>94</sup> See Section 4.2

this Scottishness in light of the discussion above. The first is a further interpretation of dwelling “Wohnen means to reside or stay, to dwell at peace, to be content; it is related to words that mean to grow accustomed to, or feel at home in, a place” (Heidegger, 1993: 345, translator’s note). In Scots, ‘stey’ is more than dwell or reside, it is to “make one’s home” (Robinson, 1985: 670). To me this suggests a certain flexibility or perhaps an ability to make oneself at home in changed circumstances. That is not to ignore the strong pull towards the homeland but does imply an inner sense of a belonging that is portable. The second point is about the last books Jane read before she died: Lewis Grassie Gibbon’s trilogy *A Scots Quair* (Gibbon, 2006). The books tell in Scots, of the light and the land, and the language; Jane summarises the story:

It’s the move from rural village small-holding through the pusillanimity of the town to industrial unrest and economic depression in the city, from pastoral idyll through civic tensions to social disintegration, that makes the later works a more difficult read. But the parallels, echoes and progressions between the three works make it clear that these are not separate books, they are three integral and inter-related parts of the same whole. (Blog post, Parallels, Echoes and Progression, day 240)

It is not clear if the central character, Chris Guthrie, dies at the end but the following extracts from the final pages speaks to both *Gegnet* and to *Heimat* as the Urphenomenon of homecoming:

Crowned with mists, Bennachie was walking into the night: and Chris moved and sat with her knees hand-clasped, looking far on that world across the plain and the day that did not die there but went east, on and on, over all the world till the morning came, the unending morning somewhere on the world. (671)

Time she went home herself. But she still sat on as one by one the lights went out and the rain came, beating the stones about her, and falling all that night while she still sat there, presently feeling no longer the touch of the rain or hearing the sound of the lapwings going by. (Gibbon, 2006: 672, final sentence)

I have come to realise that what this study does, amongst many other things, is to describe a story of coming home; to abide not just near to the primal source but at its heart, home. The study is also a validation of the Dwelling-Mobility lattice of well-being (Galvin & Todres, 2011b) as a ‘place ballet’ of aesthetic experiences. Earlier in this chapter the six phases of the phenomena of homecoming drawn from Heidegger’s synthesis of Holderlin’s poetry were listed. Goethe often used poetry in his scientific writing when he felt discursive language had reached

its limit as “Aesthetic experience can be represented only by aesthetic experience.” (Stephenson, 2005: 573). Although the extract from *A Scots Quair* is prose, it has a strong poetic quality that could be presented as a poem; for me it represents the aesthetic experience of homecoming. Returning, enhanced, to the six phases they can stand for a lifetime or a time in a life when something momentous occurred. Taking the version articulated by Holderlin then elucidated by Heidegger as the poetic journey (Mugerauer, 2008: 119), I have added (shown in emphasis) the phases of Jane’s journey, as recounted in chapters four to six:

1. an initial being at home that is not yet a being at home; at the beginning the poetic spirit is not at home in its own house *Wondering*
2. homelessness or wandering in the foreign and unhomely *Finding, Planning, Treating*
3. a turning point – back towards home – return home *Turning*
4. a moment of homecoming or arrival *Living*
5. learning to become at home in the poet's proper domain *Reviewing*
6. abiding or dwelling in the nearness of the homeland, near the primal source, near the origin *Part[y]ing, Dying*

The journey is the dance, the place ballet, the interplay between movement and rest, between dwelling and mobility. There are moments of homecoming as returns enhanced, those aesthetic experiences when there is a feeling of a serenity of mood, a vividness of presence and a heightened self awareness. And as the horizon of life draws near, there is peace in the heart of the home.

### **8.11 Summary**

This chapter has traced a convoluted path from the art and aesthetics of nursing, through German Idealism for the philosophical basis of aesthetic experience, to sociability, *communitas* and place. These ideas when combined with Heidegger’s idea of homecoming as a return enhanced, have helped to provide an interpretation of the aesthetic experience of dying.

## 9 Heart, Head and Hand

### 9.1 *Introduction*

This thesis has explored and investigated the shared experience of one woman's ovarian cancer, from diagnosis to her death eleven months later. That woman was my partner, Jane, and I was able to use in addition to my own memories of events, personal documentary materials from that time and her medical records. Fundamentally, this study has attempted to understand Jane's situation and her experience of life-limiting illness. German Idealism as embodied in Schiller's philosophical writings and many of Goethe's works, were my late partner's own area of doctoral study (Plenderleith, 1991). Her work was centred on the concept of binary synthesis as an interaction between two opposing concepts. Throughout our life together she had referred to this as a return enhanced. This concept was outlined early in the thesis and then used as a means of further exploration for some aspects of Jane's experience that emerged during her illness. This final chapter first examines the overall structure of the thesis and then considers the methodological approach. The evidence presented with regard to the research questions stated in chapter one is then reviewed, followed by a summation of the findings. The chapter concludes with the knowledge contribution of this study, its limitations and suggestions for future research.

### 9.2 *Form and Function*

This thesis is centred on three themes: a life limited by illness, aesthetic experience and the return enhanced. The first theme is the subject of the study which is then considered through the other two. Additionally, the aesthetic in the sense of style and order is reflected in the structure, and to an extent in the figurative language of this thesis. The concept of the return enhanced has also been prominent in the natural cycle of the research process. By this I mean there were many instances and occasions where I would discover an insight in the literature which was then put aside. Later, usually many months, I would return to the idea and the text with a renewed understanding of its relevance for the study. It is important to me, especially because it would have also mattered to Jane, that this thesis is well written. The language employed needs to reflect a comprehensive vocabulary and the nuanced understanding of chosen words. Within the timeframe I have not been able to make use of poetry in the way I had once hoped but I have made use of literary works both as exemplars of fine prose and to illustrate key points.

The actual structure of the thesis with its three parts and nine chapters was quite deliberate. As a framework it has served me well and is also an example of how Schiller's theory of drives can be



pragmatically utilised. There is an interplay between the material content and the structural form of that content. The thesis is a content management system for my scholarly argument on the nature of life limiting illness as viewed through lenses borrowed from German Idealism. In writing, tensions occur when it is unclear where particular sections fit and resolution when their rightful place is found. There was a further tension at the start that I could not then explain, about how this particular German philosophy might be used here. In the course of the study this tension has been resolved as I have come to understand the rhythmic patterns of the lifeworld through their “tension, intensity, and resolution” (Stephenson, 2005: 568). While the thesis is the product, Goethe would have recognised the reciprocal process of thinking and doing in its creation. For him “the link between reflection and experience, in which the aesthetic plays an essential mediating role, constituted the true basis of knowledge” (Bishop, 1999: 280). The tension of Jane’s illness and death has been resolved for me in the process of reflecting on the experience.

This process of returning to previously considered but discarded scholarly texts, to then enhance understanding is similar to Gendlin’s (2004) idea of experiencing as ‘carrying forward’. That is when something is “the reaching behind itself in going forward ... which is also the further implying that brings the further occurring” (Gendlin, 2004: 146). And this idea has been carried forward to suggest that “this kind of understanding is aesthetically inclusive and carries bodily felt implications” (Todres & Galvin, 2008: 573). So in feeling the tension between what I felt when caring for Jane, in remembering those times and in then using scholarly writing about that experience, I have perhaps achieved something akin to an ‘aesthetic phenomenology in practice’. This is characterised by the principle “the aliveness of language and the empathic use of language to facilitate an experience of homecoming for others” (Todres & Galvin, 2008: 574). I stated in Section 7.1 that “I wanted the reader to have a strong sense of the visceral reality of advanced cancer”, as the lifeworld is already “more than any category of already patterned knowing” (Todres & Galvin, 2008: 574). The challenge is to then find the language to describe this ‘felt sense’ of the experience which is “the direct referent, the implicit demanding” (Gendlin, 2004: 133). In turn this is reminiscent of Schiller’s ‘living form’ which he describes in terms of a human being in *Letter XV*:

As long as we merely think about his form, it is lifeless, a mere abstraction; as long as we merely feel his life, it is formless, a mere impression. Only when his form lives in our feeling and his life takes on form in our understanding, does he become living form; and this will always be the case

when we adjudge him beautiful.<sup>95</sup>

Beauty in this sense is the aesthetic which in Schiller's terms of the play drive acts as a harmonising force between feelings and reason, where "through beauty we become truly human" (Bishop, 2008: 144). Therefore I am arguing that it is through the aesthetic form of this thesis where the reader will feel something of the 'living form' of Jane as she experienced her illness. In turn, the reader will reach an understanding of the role of the aesthetic for humanity. To summarise, the *form and function* of the thesis was to devise a method to find and understand the aesthetic in Jane's illness experience. This was first presented as *the dance to death*, an analytic narrative account of the Illness Period. Aspects were then interpreted through the philosophical ideas of Schiller and Goethe as *the aesthetic experience of dying*. In the next section, I revisit the methodology of the study as its form and function before the following section which appraises the evidence presented in support of the research questions.

### 9.3 Methodology Revisited

The decisions regarding how this study would be undertaken and the justification for the choices made were detailed in chapter three. At the heart of the methodology was an awareness of the ethical dimensions inherent in the study. This was difficult stuff, it was about my partner and her recent death. It would use her own descriptions of events and it needed my recollections to connect them into a coherent whole. To ensure a degree of accuracy for aspects of my memories, Jane's health records were also consulted. Some aspects of the methods proposed touched on those from other studies but innovation was necessary to capture my recollections in a coherent and semi-structured fashion. The study required me to return to a series of deeply personal memories and for them to be enhanced by the gathering of new information as more detailed recollections. These data augmented the personal writings of Jane's blog and diary, and my own notes and diary.

Three questions were used to guide the methodology:

- How are lives affected by these stories?
- Why was the research done this way?
- How was the research done?

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95 WW: 101

The first draws on Frank's (2013) contention that to learn from the experience of suffering through illness, a narrative ethic is required, as outlined in the preceding paragraph. The response to questions two and three is the theoretical framework presented in chapter three which starts with a broad view of narratives of illness before centring on narrative inquiry. The theoretical orientation of the study was, from the outset, phenomenological in its objective to research a particular lived experience (van Manen, 1990). More precisely, this study is in the tradition of hermeneutic phenomenology as a "human science which studies persons" (van Manen, 1990: 6). The focus has been on the study of individual and personal experiences against the backdrop of everyday existence in the lifeworld as the other, the social and the communal. The efforts of van Manen (1990; 2007), Gendlin (1992; 2004), Svenaeus (2001; 2003; 2012) and Todres and Galvin (2006; 2007; 2008; 2010) have been crucial in reaching an understanding of hermeneutic phenomenology and the philosophical insights of Heidegger. In turn these works 'reach behind' (Gendlin, 2004) to the impact of German Idealism on Heidegger (Dahlstrom, 2004) and hence the implied influence of Goethe and Schiller.

It was the consideration of caring and pedagogy (van Manen, 1990) that led to the ethical focus of this study. Frank attests that "Because the pedagogy of suffering is taught in the testimony of illness stories, the kind of ethic it supports is a narrative ethic" (Frank, 2013: 154). I have taken this further by connecting the implicit relationship between the ethical and pedagogical concerns of Frank and van Manen to the embodied relational understanding espoused by Galvin and Todres (2011). This is a kind of knowledge, personified by the caring professions like nursing, that is "inclusive of the 'head', 'hand' and 'heart' (objective truth, actionable knowledge and empathic knowledge)" (Galvin & Todres, 2011: 523). This was interpreted as the methodological structure for this study and reordered as: heart (ethical considerations), head (theoretical framework) and hand (methods used). A final attraction to a phenomenological approach was that it enabled the study to find its own way by using methods that had to be "discovered or invented as a response to the question at hand" (van Manen, 1990: 29).

To conclude this section I will now illustrate how the metaphors of heart, head and hand, as introduced in chapter three, relate to aspects of and emergent from, the methodology. The purpose of the self-directed interviews was to gather my recollections of episodes during the Illness Period. Because I found it very difficult to just write these episodes for myself, I devised a method of interviewing using storyboards as prompts and with someone else to question me. The self-directed interview process required 'heart' to ethically explore difficult memories and

experiences. While I was aware of the potential harm or at least hurt, that might arise from these recollections, I had not fully considered the effect on the interviewer. In my enthusiasm to have someone who knew me well and who had also known Jane, I had assumed that as a trained counsellor, she knew how to cope with difficult situations. It transpired that it was actually easier for me than had been anticipated and harder for the interviewer. She had her own memories of Jane both in health and after her diagnosis. Although the advice given in a comprehensive review of ethical issues in interviews (Allmark et al, 2009) reflects the measures used here, and the interviewer herself is content with the experience, I could have been more considerate of the process than simply the acquisition of its products.

The process of writing the analytic narrative of Part Two, involved the interweaving of the evidence gathered from the self-interviews, pre-existing documentary materials such as the blog posts, and the technical evidence from the medical records. The resulting text may now be considered as more than 'head' but I find it difficult to judge. I believe that the account given in Part Two as *The Dance to Death* is an example of 'embodied relational understanding' (Todres, 2008)<sup>96</sup>. What is described in Part Two is the integration of my nursing knowledge (head) with the practical situation of Jane's illness (hand) with an appreciative understanding of her inner world (heart). This can also be interpreted as the insight that the third metaphor 'hand' has emerged from the study and its methodology, as an exemplar of the return enhanced. By this I mean the practical interplay between the experience of caring for Jane with the knowledge and understanding that I brought to the situation. Further detail can now be added to this proposition by revisiting the research questions for this study and the evidence presented to address them.

#### **9.4 The Research Questions**

Dance emerged early in the study as a metaphor first for the movement during the Illness Period and then as an understanding of the interplay expressed through binary synthesis as a return enhanced. This is the resolution of the tension between two opposing concepts, such as living and dying or thinking and feeling. Now it can also be used to interpret my experience of Jane's loss and finding resolution through this study. The research process featured many episodes of tension as I recalled all aspects of Jane's illness and each was then resolved through analytic interpretation. The study has centred on the question:

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96 See Section 3.4.2

*What can be learnt from a shared experience of living with and through a life-limiting illness?*

The thesis is my response to this question, from which I have learnt a great deal, both academically and personally. More importantly, I believe the findings are relevant for those involved in the care of those facing life limited by illness, both lay and professional carers, as well as those with personal experience of such illness. Six further questions were derived from the primary research question. The first three were addressed by Part Two of the thesis and the remaining three in chapters seven and eight, in Part Three. The evidence in response to each question is now summarised.

*1. What was the experience and in what ways was it shared?*

It could be argued that there were innumerable experiences during the Illness Period. What I have chosen to recount are a series of episodes and particular events that were for some reason more prominent. This was about a woman with advanced ovarian cancer and what it was like for her. It is also about what it was like to be her partner and walk with her to death. Part Two, *The Dance to Death* presents these multi-vocal episodes as a descriptive account that moves through three distinct phases. The narrative expressed in the rhetoric of clinical terms was of diagnosis, treatment and palliation, but as a lived experience it was about finding, living and dying. The experiential focus was on Jane as patient, initially passive recipient of health care interventions, and me as nurse never far from my previous experiences and conflicted by my now dual role as partner/carer. Yet it was that tension that led to this study, to not simply understand the medicalisation of this experience but also to exploit my knowledge of Jane and her personal philosophy. Jane's everyday understanding of binary synthesis was as a return enhanced. The negative aspects of her illness, such as dying young, could always be assuaged by returning to a positive interpretation, such as enjoying life, which dissipated the tension and restored balance as well-being. My role then could be directed to provide these positive and often aesthetic, experiential counterpoints.

*2. What is the narrative of this experience?*

The narrative of this shared experience was assembled from the multi-vocal accounts and presented as nine stories in three phases of variable duration. My writing, as opposed to Jane's or clinicians, is generally in one of two voices reflecting my dual role as partner/carer. As Jane's partner I write with heart and empathic concern for her welfare but as her carer I write as the dispassionate former nurse with clinical detachment. I have not yet recognised embodied relational understanding as an 'emotional homecoming' as a "metaphor for the emotional

recognition of a truth that is also deeply personal, familiar, meaningful and authentic” (Todres & Galvin, 2008: 569). Chapter four, *Invitation to the Dance*, describes in some detail the almost overnight metamorphosis of an apparently fit and healthy woman in her early fifties, to a woman with advanced disease. Yet the inherent tension of the diagnosis was quickly resolved by the prompt treatment plan, a good news story to render palatable the darker truth of terminal illness. Chapter five, *Days for Dancing*, covers a period of more than five months and centres on the thirteen cycles of chemotherapy and its effects. This was the dance at its most physically active with almost constant movement between hospital sessions and normal life. Within the hospital dance were different types of attendance: chemotherapy, diagnostic procedures and clinic appointments. This was counterbalanced by heightened living experiences such as hill walking and cultural excursions. The final chapter in Part Two, *The Last Waltz*, starts with the joy of a family Christmas and the painful news that the aggressive treatment regime has proved unsuccessful. In the remaining four months there is a vigorous return to living as part[y]ing, a unique time in the experience of someone who is dying. For Jane, this was when family and friends made great efforts to be with her, exemplified by longer visits, often coming from abroad, an extraordinary blend of partying and parting. Finally, as she became physically incapacitated, the dance was reduced to her stage directions of final wishes.

### **3. What are the turning points or epiphanies in the narrative?**

Turning points are essential to narrative structure as they mark the transition or transformation from the beginning to the end of a story (Mattingly, 2007). Life stories may revolve around an epiphany (Chase, 2005) as “an experience that leaves a tremendous mark on a person’s life” (Ellis et al, 2002: 189). It was in this sense that turning points were discussed in chapter seven where diagnosis is considered and found to be more epiphanic. Using turning points in one of the research questions clearly indicates that I was aware that one or more might exist within the narrative of Jane’s illness. An obvious point as it could be argued that within any illness story there will be many examples of turning points as the action moves back and forth in a dialectic between hospital encounters and normal life. I was aware of two pivotal points that I wanted to explore. The first was during Jane’s consultation with the herbalist in chapter four, a meeting that was her choice and not at another’s suggestion. The second, in chapter six again under her sole direction, was when she explicitly asked the lead oncologist how many more weeks she might expect to live. An obvious question then in this study, is what shape the narrative might have had if these turns had not been made. They can be interpreted as a binary synthesis between

acceptance and rejection. On both occasions, Jane seeks further information regarding her situation and on receiving it, returns to a more settled or balanced state by accepting her situation. Had she continued to ignore and therefore reject what was happening to her, nothing dramatic would have happened but I suggest that her remaining life would have been one of passive introspection and not the active engagement that it was in reality. In chapter eight a further explanation is proposed where *turning* can be interpreted as a phase of homecoming after wandering in a foreign place.

#### **4. What connections are there between this and similar narratives?**

The similar narratives referred to in this question are those accounts written conjointly by the illness sufferer and their partner/carer. These texts may have been published as a co-authored book (Butler & Rosenblum, 1991) or as separate memoirs by the sufferer (Lubbock, 2012) and the partner/carer (Coutts, 2014). These three sources were used as the first is about a relationship between women (Butler & Rosenblum, 1991). I have a vague family connection with one of the authors of the other two and was therefore aware of their story. While some use was also made of other accounts such as memoirs, as suggested by Frank (2013), and pathographies (Hawkins, 1993) no studies of spontaneous conjoint accounts were found. By this I mean analyses of collaboratively or concomitant narratives that have not been initiated by research. The comparisons drawn here in chapter seven are first to identify connections to Frank's work on illness narratives and then to find similar experiences in the selected memoirs. The 'bucket list' as a companion story (Frank, 2010) is explicated as a series of landscape-based adventures either hill-walking or visiting gardens. The common thread is regular immersive contact with nature.

Comparisons with narrative types did not rely solely on Frank's typology (2013) of restitution, chaos and quest but it did find them to be the most compelling. One reason for this preference could be that Frank's style (2010, 2013) exemplifies embodied relational understanding (Galvin & Todres, 2011). He writes with the perspective of personal illness and not as a health care practitioner yet does so in a way that is nevertheless indicative of head, hand and heart. Examples of all three narrative types were found within Jane's writing as well as in the other memoirs which suggests there is a commonality in the way illness is narrated by its sufferers. However, reading illness accounts for their categorical fit may lead to misinterpretation by isolating incidents from the narrative whole. A further issue concerns the gathering of illness accounts which rely on researcher-led interviews. This shifts the narrative purpose from situated personal understanding and resolution to an academic exercise however well-intentioned.

Narrative in the context of illness has an important, therapeutic role particularly with regard to the acceptance-rejection dialectic but the impetus for it needs sensitivity.

##### *5. What relevance does place have for this experience?*

At the start of this study I had a sense that certain places were special to Jane but I wanted to explore the extent to which this was simply a preference for the familiar or something deeper. This sense was partly influenced by my own feelings of displacement in the months preceding Jane's diagnosis when we were in a state of flux and between homes. The disruption of the diagnosis was not just biographical (Bury, 1982) but spatial as evidenced by the various references in chapter four that alluded to our accommodation; it ranged from staying with Jane's mother, to nights in hotels and guest houses, to finally moving into our new flat. Yet to reduce place to spatial position is to forget being (Relph, 2008). Many places feature in Jane's blog as in her descriptions of excursions and hill-walks. 'Place' the word, occurs in one post first as "so many friends in so many different places" and then "there's something particularly special about showing a special place to someone else" (Blog post 'Portobello', day 47)<sup>97</sup>. These two quotations perhaps illustrate the distinction Heidegger (1958) makes between the two dimensions of place in which we exist. He proposes an outer, horizontal aspect that is determined by our political, social and economic relationships or more simply, our place in the world. This horizontal dimension is then intersected by a vertical aspect that reveals the depths of personal freedom and reality. Heidegger continues to expand his theory:

The vertical dimension of being is the house of Being from which meaning and structure arise and become constitutive of the horizontal dimension. The two dimensions appear in separation but are housed in unity and reveal each other to each other. (Heidegger, 1958: 19)

Hidden in the complexity is the idea that place is not simply spatial position but also in the ontological sense of being in-place. At any point in our time we are at an individually unique intersection between physical location and our being in-place. So a more accessible definition would be "It is a complex unity, integral to being, and encountered experientially as simultaneously unified, differentiated from yet connected with other places, and gathering together things, people, and our own lives." (Relph, 2008). In Jane's quotations above, there is both physical location (friends in different places; a special place) and the simultaneous, differential connection to others.

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<sup>97</sup> Section 7.3 has a slightly longer extract of this quotation.



Perhaps the most significant place in this study is the home, conventionally as the spatial dwelling place, the flat where we lived and Jane died. But it also symbolises the sense of feeling at-home first identified in chapter four when I describe the need to make the flat habitable for Jane's comfort. Then I recognise the sense of unhomelikeness first from our travelling about and then through the existential displacement of illness. The theme recurs in chapter eight and is first explored through the concept of at-homeness and the feelings of dis-ease that may arise when adjusting to new places. The discussion then moves on to identify home as a sacred place and the threshold for the transition between life and death. Depictions of place range from the wide horizons of the Scottish landscape to the innermost sanctum of home with its walnut bed. Equally, home is a place of homecoming and homeland.

#### **6. What was the role of German Idealism in the emergent narrative?**

Clearly this is a broad question and was never intended to encapsulate German Idealism in its entirety. The expression is used here as shorthand for the philosophical ideas of Goethe and Schiller as detailed in the second part of chapter two. The justification was based on my personal understanding of Jane's scholarly interests as evidenced in her own doctoral studies (Plenderleith, 1991). This was outlined in Section 1.4 where I introduced the methodological tool she had used, binary synthesis, which she always referred to as a 'returned enhanced'. Subsequently in Section 2.3.2, I described the historical context of the relationship between Goethe and Schiller. This was followed by a detailed explanation of Schiller's *Aesthetic Letters*, as the core text in which binary synthesis and the influence of Goethe's scientific ideas on Schiller's theories, are explicated. In the *Aesthetic Letters* Schiller sets out his theory for the good life through the enhancement of everyday life. He believed this could be achieved through the aesthetic appreciation of beauty as a moral imperative. The form of Schiller's writing can be seen as a precursor to embodied enquiry (Todres, 2007) which seeks a balance between the texture of the writing as a rich description of experience with an aesthetic dimension, and the bounded, inner logic of its structure. In the *Aesthetic Letters*, Schiller is writing about beauty as a synthesising concept between experience and reason. He uses the structural technique of binary synthesis to present his argument as the interplay between two basic human forces: the sense-drive of feeling and the form-drive of thinking. The tension between these two polarising forces necessitates a third mediating force, the play-drive which he calls beauty. It is only in a later and minor work on gardening, that Schiller moves from the abstract notion of beauty as an art form to recognise that aesthetic order can apply in other contexts such as the landscaped garden.

Initially, Schiller had followed Kant in thinking in terms of a dualism between nature and freedom. However, Goethe is credited with encouraging Schiller to reconsider his concept of wholeness, not as a static state but one that changes over time. The relationship between Goethe and Schiller was enhanced by their complementary dispositions. Schiller relied on abstract ideas while Goethe preferred to work from the close observation of a phenomenon to then develop an understanding of the whole. Two important examples of Goethe's scientific studies are first his idea of the primal plant as the essential nature of all plants of which Schiller was dismissive. Goethe's response was to be more systematic in his scientific work which helped with the second example, his theory of colour. Relevant to this context is not the colour theory but the way in which it was presented in the text as a state of mind which merges thought with perception. In this state the Urphenomenon or primal phenomenon can be perceived, simplistically as the glimpse of something as a bigger whole. This form of understanding has now been implicitly 'carried forward' (Gendlin, 2004) in the appreciative awareness of the relationship between theory and practice, structure and texture, head and heart; to facilitate the understanding of the human experience (Todres, 2007). German Idealism, as presented in the *Aesthetic Letters* and the philosophical ideas of Goethe and Schiller, has reached a nexus with a phenomenology of practice. This can be understood as a different way of knowing the world where "language needs to remain oriented to the experiential or lived sensibility of the lifeworld" (van Manen, 2007: 20). In this thesis the concept of binary synthesis has enabled a deeper, more holistic understanding of living and dying through the emergence of aesthetic experience. The final section to this chapter and to the thesis, expands and concludes this point.

## 9.5 Conclusions

For some, completing a doctorate can cause the candidate to freeze "unleashing a wave of incapacitating confusion" (Brabazon, 2010). I find myself paralysed not by confusion but by what closure will mean. This study has not only kept Jane alive and in the foreground but has also satisfied my intellectual desire to understand binary synthesis. The latter may well serve me in future research but ending the former is a surprising struggle. The enormity of finally letting go lifts my hands from the keyboard as I try to write. One last push, head over heart. So in this final section I will first summarise the knowledge contribution and implications of this study, particularly to the field of phenomenological practice. The limitations of the research in terms of its data and methods are then reviewed. Finally the opportunities for further research are summarised.

### 9.5.1 Contribution to Knowledge

The contribution of this study can now be seen as a novitiate form of embodied enquiry where the “complementary tension between academic and more poetic forms of writing” (Todres, 2007: 57) has been used without detriment to scholarliness. What this study adds to what is known about death, dying and German Idealism can now be presented within the simple structure of head, hand and heart but reordered to reflect the three parts of the thesis: hand, heart and head. I will first consider the contribution of the methodology to the practical doing or hand of the study, then moving on to the heart as the *Dance to Death*, before concluding with the head as the *Aesthetic Experience of Dying*.

### 9.5.2 The Methodological Hand

Initially this study was driven by the documents I had to hand, the notes, dairies and blog posts from the Illness Period. I had assumed that in terms of method I would connect these artefacts by infilling the gaps in the stories from my recollections. Yet each time I tried to start writing I would essentially recount the time when Jane’s illness was found with varying degrees of back story. My solution was to devise the self-directed interview method. This had the inherent advantage of freeing me as researcher to be in touch with the felt-sense of my experience as bereaved partner. Having someone else directing the dialogue between the storyboards and my recollections allowed the tension between events and memories to be resolved. My attention was deflected from the framework of the storyboards (head) by the interviewer (hand) to the inner world of my memories (heart). Interviews conceived in this manner may be helpful to researchers when considering their own interpretations and use of this method.

The process can also be interpreted as a return enhanced, the interplay between recalled experiences and the rationalisation of those memories. With each iteration between the two, a step forward is taken towards resolution from the intensity of trying to understand. This approach underlies Part Two where the experience of the Illness Period is contrasted with the academic literature and presented as an analytic narrative. Yet it is important to recognise that while the use of analogy and metaphor can be useful tropes in carrying difficult ideas forward, they can also be impediments. There is an inherent trap in the false configuration of concepts for the sake of appearance and not for rational argument. This would be ‘enhancement’ without

appropriate ‘specification’, as Jane termed it.<sup>98</sup> She was recalling Goethe’s discussion of the two principles at work in the growth of any form: metamorphosis and specification (Wilkinson & Willoughby, 1962). She simplified the awkward term metamorphosis and instead used *enhancement* which can be understood as the tendency to change. In a similar vein, specification is “the tendency to persist in specific form” (Wilkinson & Willoughby, 1962: 151). Sontag’s use of the metaphor, “the kingdom of the ill” (Sontag, 1978: 3) as a conceptualisation of illness, is one such impediment.

While the methodology in this study has not made direct use of the intricate word plays employed by Goethe and Schiller, it has been informed by the harmonious nature of their approach. This has added an intuitive sense of the aesthetic to the form and content of the study. This might be summarised as “what makes it aesthetic is the *co-ordination* of the abstractions of the understanding with what is presented to sense, as opposed to our ordinary, everyday, imaginative activity in which the latter is *subordinated* to the former” (Stephenson, 1983: 162, original emphasis). In other words experience rises above cognition and enhances understanding. I suggest that the method used in the design of the thesis is also a contribution to knowledge as it reflects Schiller’s theory of the drives. The first part of the thesis is essentially setting the scene and the case for the two subsequent parts. Part Two is then concerned with experience and therefore connects with the sense-drive while Part Three is about reason and understanding as the form-drive. The aesthetic emerges as the interplay or play-drive between the two parts.

### 9.5.3 Dwelling on the Dance to Death

The dance to death is now understood as the movement between the life necessitated by illness and ‘normal’ life, as it was otherwise known. The diagnosis of life-limiting illness can be interpreted as a turning point but as I described in Section 7.8, it is more like a threshold and therefore an entrance to the sacred world of the dying. In this place it can be difficult for family and friends to know how to respond, therefore one of the contributions of this study is to demonstrate how the dance can work. The rich descriptions of daily life in Part Two are contiguous with the Dwelling-Mobility lattice (Galvin & Todres, 2011). This study has not attempted to validate the framework as such but it has identified connections through the ‘place ballet’ of aesthetic experiences. The study has also hinted at the sense of homecoming that the bereaved partner might find through an active reappraisal of their shared experience of the life-

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98 We gave a joint paper on e-learning at the 2005 Online Educa Berlin Conference where Jane used these terms.

limiting illness of a loved one. However, I would not recommend that such work be undertaken unaided but that it is supported in some way. Nor am I suggesting that the exploration would necessarily be narrative; there are many other equally suitable forms of creative expression. In the shared experience of life-limiting illness there is movement in the well-being of daily life and there is peacefulness, content to dwell at-home both spatially and experientially.

A further connection can now be made between the head-hand-heart construct as the scholarly integration of actionable knowledge (Galvin & Todres, 2007), Heidegger's essay *Building, Dwelling, Thinking* (Heidegger, 1993) and Schiller's drives. In making the connection the inter-relationship of the domains can now be better understood in terms of the binary synthesis at work between them. The following table and the diagram at *Appendix 9: A Return Enhanced*, illustrates the relationship between these terms, their sources and essential meaning:

Heidegger	Galvin & Todres	Schiller	Interpretation
Dwelling	Heart - ethics	Sense-drive	Being present, the manner of, and aware, peaceful safeguarding
Building	Hand - art of action	Play-drive	Enhancement: as cultivation and construction
Thinking	Head - knowing	Form-drive	Cognitive reasoning

**Table 9.1 Scholarly Integration of Actionable Knowledge**

If the relationship between thinking (head) and dwelling (heart) is conceived as a binary synthesis, building (hand) can be understood in terms of its mediating role in the interplay between the other two. Either thinking or dwelling will be subordinated by the other. The process will be harmonised when building is done with a sense of peaceful safeguarding or ethical awareness. Heidegger states that humankind will accomplish this “when they build out of dwelling, and think for the sake of dwelling” (Heidegger, 1993: 363). When our actions have an ethical dimension, we know we have acted for the greater good. A practical interpretation of these ideas appeared in Section 7.7, when I suggested that the enhancement of death and dying may be at odds with the therapeutic desires of those involved. Recognising a wider range of healing opportunities that are centred on well-being such as those proposed regarding aesthetic experience could help to address the imbalance some feel results from an overly technical medical model.

#### 9.5.4 Rethinking the Aesthetic Experience of Dying

The final aspects of this study which make a contribution to scholarly knowledge, possibly to nursing in both the professional and lay sense, is the interpretation of aesthetic experience derived from this research. Aesthetic experience was defined in chapter eight, as a feeling of serenity of mood, a vividness of presence and a heightened self-awareness. The case was then made for particular aspects or characteristic dimensions which might enhance the appearance of such feelings. In the context of someone who is dying, these moments of exquisite wholeness may arise from sensations that are experienced in relation to particular places. Drawing on Simmel's notion of sociability and Turner's theory of *communitas*, these feelings may provide a sense of a return enhanced to everyday, secular life from the sacred place of dying. Awareness of the integrative nature of head, hand and heart avoids artificial contrivance and the spontaneity of aesthetic experience emerges naturally.

It is worth noting, as suggested in Section 7.9, that the dying person may recognise that state for themselves much sooner than any formal prognostic indication is given. Consequently, an appreciation of this interpretation of aesthetic experience may provide an additional means of support relevant to both family and friends as well as health care professionals. The contributory aspects to the emergence of aesthetic experiences are summarised with their key sources:

- a sense of at-homeness, a sacred, peaceful place – Heidegger, Seamon
- the inner court of family and friends that provides a context for sociability – Turner, Simmel
- heightened sensory awareness experienced as moments of pleasure through taste, touch, smell, sound and sight – Schiller, Simmel

#### 9.5.5 Limitations of the Study

There is a temptation to suggest that one of the major limitations of this study has also been its strength. That is its personal nature and my relationship with the woman who is the subject of the study. This may raise concerns regarding a potential lack of objectivity in the analysis and conclusions. However, I have made every effort to be rigorous in my approach through the systematic application of methods and modes of analysis. In designing any study, many choices are made including the selection of appropriate data subjects and in determining the boundaries of the inquiry. With this study it may appear that the choice of subject was inevitable and there

were no alternatives, it was always going to be about Jane and her illness. While this may be true, the study could have taken other routes to understanding the shared experience of life-limiting illness that are described here. I am discounting as different studies those that would have used different respondents as the central subject of interest. Accepting the subject as given, others involved in Jane's care could have been interviewed to provide a broader view of her experience. A more clinical approach might have been to focus on particular aspects of nursing intervention and their effect on aesthetic experience.

With hindsight I now wonder if it would have been better or just different to have merged our voices in writing the episodes for Part Two. There may be other ways in which the narrative could have been approached but I wanted to find a balance between being true to the experience and sufficiently scholarly for a doctoral thesis. The timing of the research was clearly a factor in determining the approach as the study started within a few months of Jane's death. At that time I know I was both driven and distracted. To start afresh now would again be a different study, less visceral, more considered but not necessarily better. I had intended suggesting that I would have worked more with the Dwelling-Mobility lattice (Galvin & Todres, 2011) and more consciously within a framework of embodied enquiry (Todres, 2007). However, in the approach I have taken, I believe some relevant connections have been identified that trace those ideas further back than Heidegger to their origins in German Idealism.

#### **9.5.6 Future Research**

This now feels more like the beginning than the end of the study, as the potential for further work seems more tangible. In addition to a range of ideas for further study, this thesis has also presented some innovative approaches which future researchers may wish to pursue. For example, the self-directed interview method for accessing difficult experiences can be adapted to other situations and contexts. Novice researchers may also find helpful the interpretation of the scholarly knowledge relationship as a binary synthesis of head-hand through heart. Proposals for future studies are now summarised:

- Enhancement at the end of life in a more natural and less technological sense
- Exploration of the range of aesthetic experiences and the potential of technology for their provision

- The extent to which the concept of the return enhanced can inform understanding in the relationship between theory and practice, as both/and not either/or
- The relevance of the interpretation of aesthetic experience emerging from this study in real-life settings

## 9.6 *Summary*

This study has explored in considerable detail one woman's experience of ovarian cancer, from diagnosis to death. It has traced a path through that experience using insights drawn from 18th century German Idealism as an understanding of the aesthetic. It is not a study of life and death but of living and dying with a spirit of well-being. This is encapsulated in the emergence of aesthetic experience through the related aspects of place, people and perception. Recalling the earlier reference in Section 8.6 to Goethe's world of beautiful imperfections is also a reminder of human finitude. In the context of Japanese culture and aesthetics, this is exemplified by the annual celebration of the cherry blossom as a symbol of life's impermanence (Juniper, 2003). As a study of life, love and loss, this thesis may well be full of beautiful imperfections. Better then to give Jane the last words "I admire the courage it takes to commit to paper how you feel about someone, what they have meant to you, what you have learned from them" (Blog post, 'So Much Love', day 330).



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## Appendix I: Doctoral Studies Reviewed

Author/Degree	Dissertation Title	Year	Institution	Extract from Abstract
Bentley, Susan M PhD	Friedrich Schiller's Play: A Theory of Human Nature in the Context of the Eighteenth-Century Study of Life	2009	University of Louisville	Friedrich Schiller's psychological theory of play, his hypothesis about human nature, is embedded in the Aesthetic Letters. Its trans-historical value owes much to the committed interest in life in the late Enlightenment, and the theory itself is an example of that period's enthusiastic study of living organisms. It is within the context of eighteenth-century natural history, natural philosophy and medicine that the theory can be profitably evaluated. It is also an example of the connection of the humanities of the time and the emerging life sciences suggests its usefulness as a paradigm today: as a general theory of human nature, it might serve as a bio-cultural ground for the humanities. Today, humanists can choose to play with our century's biological sublime: we can, for example, grab hold of its theories and its data to put Schiller's theory into play.
Carper, Barbara A Doctor of Education	Fundamental Patterns of Knowing in Nursing	1975	Teachers College, Columbia University	The genesis of this study is derived from the thesis that the body of knowledge that serves as the rationale for nursing practice has patterns, forms, or structure that serve as horizons of expectations that provide the discipline with its particular perspectives and the understanding of these patterns is essential for the teaching and learning of nursing. The four fundamental patterns of knowing, identified and abstracted from the analysis of the conceptual and syntactical structure of knowledge in nursing are distinguished according to the logical type of meaning and designated as: (1) empirics, the science of nursing, (2) esthetics, the art of nursing, (3) the component of personal knowledge in nursing, and (4) ethics, the component of moral knowledge.

Author/Degree	Dissertation Title	Year	Institution	Extract from Abstract
Copp, Gina PhD	Facing impending death: the experiences of patients and their nurses in a hospice setting	1996	Oxford Brookes University	This thesis provides a prospective account of a defined period in the lives of twelve individuals dying in a hospice. The primary focus is on the patients construction and management of their experiences in confronting impending death, and on their nurses' experiences in caring for these individuals as they died. In interviews with patients whose death was imminent, and with their nurses, reference was often made to the 'body' as separate from the 'self'. In particular, the nurses' constructions of a body-person split were made by direct reference to the body as a separate entity from the personal self in attempts to gauge the patient's 'readiness to die'. This 'readiness to die' conceptual map appeared to be characterised by the following four modes: person ready, body not ready; person ready, body ready; person not ready, body ready; person not ready, body not ready.
Cotter, Angela J E PhD	Wounded Nurses: Holism and Nurses' Experience of Being Ill	1990	South Bank Polytechnic	One important creed of holism, as currently interpreted in orthodox medicine and nursing, is that the health of the health worker is important: 'physician heal thyself'. The 'wounded healer', however, is a concept which decorates the fringes of this holistic health and medicine debate. There has been little exploration of the experience of those health workers who have suffered illness . The thesis begins by setting the general context for the fieldwork which is an investigation of the experience of a group of nurse-patients.
Cotterell, Phil PhD	Living with life limiting conditions: A participatory study of people's experiences and needs	2006	Brunel University	This thesis is focused upon experiences of living with life limiting conditions. It aimed to gain accounts from people who, potentially, had palliative care needs, to highlight a range of experiences of their lives and conditions and to identify what these service user needs might be. Themes of diagnosis, fear, anger/frustration, grief, relationships. services,

Author/Degree	Dissertation Title	Year	Institution	Extract from Abstract
				<p>difference/individuality and independence/dependence were identified. As well as being a distinct theme in its own right, independent/dependent was in fact a central and overarching theme with a negotiation between independence and dependence being evident across all themes. The theme of services is presented as a theme in its own right. The participatory approach revealed themes unlikely to have been identified by myself as a sole researcher. It also led to service user outcomes being identified and largely positive appraisals of their involvement in the research.</p>
Froggatt, Katherine A PhD	Keeping the balance: hospice work, death and emotions	1995	South Bank University	<p>Nurses working within the hospice movement daily embrace death as the focus of their work and a concept of the 'good' death influences how nurses manage the life-death boundary, so shaping the care they give to dying and bereaved people. In their relationships with dying people and their kin, nurses undertake a form of emotional work and similar emotional resources are drawn upon by nurses in their experience of personal loss. It is this juxtaposition of the professional with the personal in experiences of death, which forms the focus of this study.</p> <p>A rites of passage model provides a framework to explore the hospice culture and the role of nurses as ritual specialists. Nurses facilitate the dying passage for people and their families through the transition between life and death. Keeping a balance emerged as being a significant concept for hospice nurses' work with death and emotions.</p>

Author/Degree	Dissertation Title	Year	Institution	Extract from Abstract
Furber, Lynn PhD	Investigating interactions: how do doctors and patients experience the disclosure of significant information in the advanced cancer setting and how do these experiences enhance practice?	2010	University of Nottingham	This thesis focuses specifically on the transmission of bad news from doctors to patients and their families in the context of a hospital oncology department. It uses awareness context theory as a basis for exploring communication between patients and health care professionals, particularly when the information to be disclosed is sensitive and will have a significant bearing on how people perceive their future. The insights gained from this study are presented in relation to two main analytic themes; Doctors and Patients Acting their Parts, and Sharing Uncomfortable News.
Gaydos, H Lea Barbato PhD	Illuminated Lives: Co-created Portraits of Contemporary Women Healers	1999	The Union Institute, Ohio	This study combined personal narrative and visual art in a process developed by the researcher to explore the question, What is the lived experience of contemporary women healers? Three women healers were interviewed. With each healer, the researcher and participant cocreated a visual image of the healer's life journey. Use of a new research method developed by the researcher, cocreative aesthetic inquiry, revealed a unity of meaning for each life from themes in the individual narratives combined with the metaphors and symbols in the visual portraits. Cocreation was found to have five aspects: engagement, mutuality, unknowing, movement, and new form. These aspects are not sequential or hierarchical, but exist in relation to each other.
Higgins, Edwina PhD	German aesthetics as a response to Kant's 'Third Critique': the thought of Friedrich Schiller, Friedrich Holderlin and Friedrich Schlegel in the 1790s	2008	Cardiff University	Germany in the years immediately after the publication of Immanuel Kant's third critique - <i>A Critique of the Power of Judgement</i> . Besides many comparatively minor developments, it identifies three important changes in aesthetic thinking after Kant. Firstly, there was an increased emphasis on the integrated and interdependent nature of the human thinking that Kant

Author/Degree	Dissertation Title	Year	Institution	Extract from Abstract
				had been more concerned to classify and analyse. Secondly, the change in aesthetics marks the change from Enlightenment classicism to Early German Romanticism. Thirdly, the role of aesthetics itself changed, from attempting to define the concept of beauty and explain how we perceive it, to claiming that aesthetics is concerned with humanity's search for meaning in the work of art.
Hockey, Jennifer PhD	The Human Encounter With Death: An Anthropological Approach	1986	University of Durham	<p>The thesis explores the quality of death-related experience, that is the semantic resonance of acts, events and utterances taking place in time and space framed predominantly by death. It draws on an anthropological/hermeneutic understanding that meaning arises out of the relationship between an act/event/utterance and its cultural and social setting. The source selected is Ricoeur's work on the relationship between text and context.</p> <p>The three areas selected for study through participant observation are (1) Hospice death (2) ageing in residential care (3) bereavement. These contexts reveal the limits of a medical model of the relationship between life and death.</p>
Hughes, C R PhD	Palliative Care in Context: An Ethnographic Account of the Journey From Diagnosis to the End of Life	2009	University of Canterbury, New Zealand	<p>This study of palliative care in context was conducted in a major New Zealand city and examines the journeys of eight people with a life-threatening illness and the journeys of 83 members of their families. The information gathered from the years spent in the field is presented in chronological fashion and divided into four primary topic areas: a narrative exploration of diagnosis, the changing landscape that participants encounter, the embodiment of new places and spaces, and finally, the journey's end. The themes from the four topic areas contribute to the</p>

Author/Degree	Dissertation Title	Year	Institution	Extract from Abstract
				development of the two core categories “time and place” and “preparedness for death”. A schematic representation of the paths participants took is provided in the discussion of the core categories.
Hussey, Charlotte A PhD	Of Swans, The Wind and H.D: An Epistolary Portrait of the Poetic Process	1999	McGill University, Montreal	This dissertation is a qualitative case study of a woman's poetic process. Rather than examine creativity from the outside, I have viewed it from the inside in an attempt to document my direct engagement, as an emergent woman poet, with my own writing. I have conducted personal, poetic research throughout this project in an attempt to construct a self-portrait of my own creativity. To do so I have not attempted to prove a thesis, or strive for scientific objectivity. Chief among the heuristics I have employed was a yearlong fictive correspondence that I entered upon with the Modernist poet, H.D. [Hilda Doolittle].
Johnston, Bridget PhD	Perceptions of palliative nursing	2002	University of Glasgow	This thesis describes a three-year study which explored the lived experiences of nurses delivering palliative care, and dying patients receiving palliative care. The aim of the study was to examine the perceptions of patients and nurses regarding palliative care, and in particular, how they described a good palliative care nurse. The lived experience of palliative nurses was characterised by effective and ineffective interpersonal communication, the building of therapeutic relationships with dying patients, attempting to control pain and distressing symptoms, endeavouring to work as an effective multi-disciplinary team with their colleagues, and developing knowledge and experience in palliative care.

Author/Degree	Dissertation Title	Year	Institution	Extract from Abstract
Jones, Kip PhD	Narratives of Identity and the Informal Care Role	2001	De Montfort University	Questions of continual and/or repetitive informal caring and the part childhood, development and personality play in adult caring roles form the background of the research's focuses on why individuals gravitate toward the informal care role and why they continue to care in the face of overwhelming obstacles. The investigation explores how informal carers create meaning in their everyday lives expressed through actions. Biographies are seen as representations close to those actions, therefore, a biographical narrative interpretive method is proposed to address the questions.
Newbury, Margaret J Doctorate in Health	The Carer's Initiation: A qualitative study of the experience of family care of the dying	2009	University of Bath	The aim of this study was to explore the experience of carers of family members dying at home with particular reference to their expectations and preparedness for the dying process. It was a qualitative, longitudinal study, however, as a theatrical metaphor became apparent from the data the approach changed to dramaturgical analysis. Carers were found to be performing a leading role in home palliative care but they experienced a universal sense of uncertainty and of being unrehearsed for their role in the dying process. They needed the direction of health professionals and the support of paid carers but had variable experiences of these services.
Smith, Paula C PhD	Family caregivers in palliative care: perception of their role and sources of support	2000	University of Southampton	Although previous literature has examined family caregiving in a number of environments, there has been a lack of information and understanding of the nature of family caregiving within palliative care. Two studies were undertaken to establish the expected and actual role and position of family caregivers in palliative care, from a health professional and lay person perspective. The findings reveal that family caregivers in palliative care settings are frequently in an ambiguous position. Whilst they are

Author/Degree	Dissertation Title	Year	Institution	Extract from Abstract
				considered essential to the well being of a palliative care patient, there are little or no guidelines for health professionals as to the role of these individuals within a total package of care.
Stehle, Peter A PhD	The Caregiving Relationship: Palliative Caregivers' Relationships with Patients and Families	2001	City University, London	The purpose of this study was to investigate the relationship and communication experiences of hospice caregivers with patients and families. Two research questions were addressed: How do caregivers experience these relationships and what is the nature of this relationship?, and what role does communication play in the development and maintenance of these relationships? The themes of communication that were identified in this study as well as the subthemes and the communication problems that arise in this context are all part of the meta-theme of preparing the patient/family unit for the occurrence of death.
Toombs, S Kay PhD	The Meaning of Illness: A Phenomenological Approach to the Patient- Physician Relationship	1990	Rice University, Houston	This work provides a phenomenological account of the experience of illness and the manner in which meaning is constituted in the physician-patient relationship. Rather than representing a shared reality between physician and patient, illness represents two quite distinct realities - the meaning of one being significantly and qualitatively different from the meaning of the other. A phenomenological analysis of body reveals that illness is fundamentally experienced by the patient as a disruption of the 'lived body' rather than as a dysfunction of the biological body.



## Appendix 2: Binary Synthesis

In an attempt to further explain and assist with understanding Schiller's concept of human drives as described in the *Aesthetic Letters*, Wilkinson and Willoughby, the translators supply an illustrated appendix using simple triangles to indicate the relationship between each pair of concepts. However, the convention has not been widely adopted with most Schiller scholars relying on purely textual descriptions (see for example, Sharpe, 1991; Beiser, 2005; Curran, 2005). Even when the actual term 'binary synthesis' is used text, is preferred to figures (see for example, Plenderleith, 1993; Stephenson, 2005). However, Bishop (2008; 2008b) does, on occasion, resort to the same technique as employed by Wilkinson and Willoughby (Schiller et al, 1967). In three doctoral dissertations (Plenderleith, 1991; Higgins, 2008; Bentley, 2009) where the *Aesthetic Letters* or binary synthesis form a significant part of the thesis, only one makes use of illustrations (Higgins, 2008). But in this instance the figures are the author's own device and the text makes no reference to binary synthesis despite numerous citations of Wilkinson and Willoughby (Schiller et al, 1967). Nevertheless, while Plenderleith (1991, 1993) does not use the device herself, she was known to have used it in association with others<sup>99</sup>. Informed by both the original concept (Schiller et al, 1967: 349) and subsequent use (Bishop, 2008, 2008b) the following diagrams demonstrate the use of triangles as a visual aid to the original conception of binary synthesis and as interpreted in this study.

### Wilkinson and Willoughby Original Concept

This is the type of synthesis employed by Schiller showing the reciprocal relationship between the pairs from which a 'third thing' can emerge, as a kind of fusion but not strictly as a binary synthesis.



Figure 1: Schiller Type Synthesis

<sup>99</sup> We gave a joint paper on e-learning at the 2005 Online Educa Berlin Conference where triangles were used in a similar manner to those here.

It is similar to the type of synthesis as interpreted by Goethe as a true binary synthesis where the term at the apex is the same as one of those at the base. Capitals are used to indicate that it is a higher concept, embracing both the limited form of the same name and its opposite. Either of the terms can move to the top.



Figure 2: Goethe's Binary Synthesis

### The Dance to Death

These three examples are taken from Part Three of the thesis where the concept is developed. All three are indicative of the central idea that there is a process at work (the play-drive) where the opposing concepts are held in dynamic tension that intensifies and is then resolved through mutual subordination, first one, then the other. As a dynamic process it is similar to a spiral where at each turn a step nearer is made, to whatever the ultimate goal, purpose or outcome might be. The obvious example is dying, that ends with death.

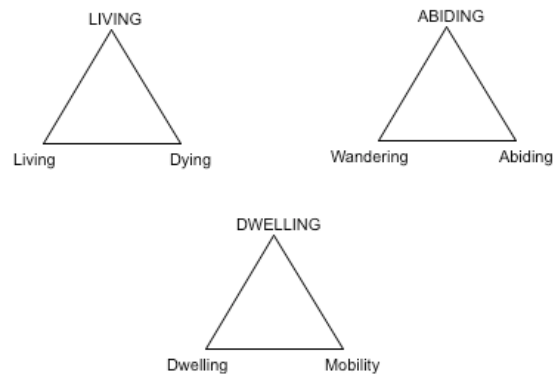


Figure 3: Binary Synthesis Exemplars from the Dance to Death

## Appendix 3: Memorandum of Understanding

### Memorandum of Understanding Between [Research Student] & [Interviewer]



#### **The Dance to Death: the Aesthetic Experience of Dying**

##### Part 1: About me and the purpose of this study

I am a doctoral student at the University of Edinburgh in the School of Health in Social Science. I am exploring the shared experience of living alongside and through a life-limiting illness that contributed to a good death at home. I am using a single case study approach that draws on both personal narratives and the wider institutional context. Part of the research necessitates gathering my personal recollections of particular events and turning points in a wider narrative from diagnosis to death.

You have been invited to participate in this project because you have previously expressed a willingness to act as an interviewer to facilitate the gathering of these personal stories. It is anticipated that there will be twelve interviews. As there is a contractual element to this potential arrangement the second part of this document is a memorandum of understanding between me, the researcher and respondent, and you, as the interviewer. Please read this document and ask any questions about anything that is unclear to you or that you do not understand before deciding whether or not to participate in this project in the terms set out below. At the end of the document you are asked to sign a copy to indicate that you have read and agree with the terms as described.

##### **Part Two: Memorandum of Understanding (MOU)**

Nothing in this memorandum shall be construed as creating any legal relationship between the two named parties. This memorandum is a statement of collaboration and evidence of the agreement between the Interviewer and the Research Student for the study as outlined. The purpose of this MOU is to formalise the relationship between the two parties and to commit each party for the duration of this agreement. It is effective from the date of signing and will last until all interviews are agreed to be completed or by August 2015 at the latest.

##### **Description of Services**

The Research Student agrees to:

- Provide a briefing document or story board for each interview

- Be open to comments and feedback from the Interviewer regarding the process and conduct of the interviews
- Remunerate the Interviewer for their services at a reasonable rate similar to that paid for counselling services
- Accept the Interviewer's professional opinion regarding the Research Student's well-being
- Terminate this agreement should either party feel that it is not working for whatever reason

**The Interviewer agrees to:**

- Conduct unstructured free-narrative style interviews with the Research Student for the sole purpose outlined above; it is anticipated that each interview will last at least an hour
- Accept the content of the interviews is confidential and may not be divulged to third parties without the permission of the Research Student except for the sole purpose of the Interviewer's own supervisory relationship
- The intellectual property of the interviews belonging to the Research Student
- The interview being digitally recorded by only the Research Student and not by the Interviewer
- Keep any notes made during an interview securely and only for as long as is necessary for the interview process
- The use of their professional premises for the conduct of the interviews if requested
- Terminate this agreement should either party feel that it is not working for whatever reason

This research project is conducted under the terms of the ethics procedure of the University of Edinburgh, School of Health in Social Science. Any other queries or comments specific to this study can be directed to either of my supervisors Professor Tonks Fawcett (T.Fawcett@ed.ac.uk or 0131 650 3883) or Dr Marion Smith (marion.smith@ed.ac.uk or 0131 6551 3966).

The named parties jointly agree to this Memorandum of Understanding and to the provisions as set out above. There will be two copies of this memorandum equally valid, one for each party, effective from the date of its signing.

<b>Interviewer</b>	<b>Research Student</b>
Name:	Name:
Date:	Date:

## Appendix 4: Illness Period Time Line

Day	Month	Storyboard	Story	Key Events
1	June	1	Wondering	Train journey
3		1		NHS 24 Consultation
21	July	1		GP referral
22		2	Finding	Ultrasound diagnostic laparoscopy
23		2		Formal diagnosis
30		3	Planning	Oncologist first meeting
31		3	Treating	Chemo Regime 1
76	August	4		Review CT Scan
91	September	4	Turning	Herbalist meeting
92		4		Psychologist meeting
104		4		Chemo Regime 2
118	October	5	Living	
174	December	5		Surgeon review meeting
175		5		Family Christmas
198		6		Final chemo session
199		6	Reviewing	
232	February	7		Review laparoscopy
260		7		Oncologist review no further treatment
261	March	7	Part[y]ing	
267		8		GP initiates palliative care
273		8		Ascites drained
279		8		Marie Curie nurse first meeting
282		8		District nurse first meeting
286		9		PleurX drain insertion
289		9		Hospital admission blood transfusion
304	April	10	Dying	Syringle driver 1 with anit-emetic
322	May	10		Hospice overnight, syringe driver 2 with opiate and sedative
343		11		Death

## Appendix 5: Blog Post

### Coping with Chemo (Day 159)

One of the things we found most disconcerting about my cancer diagnosis was the official advice effectively banning vitamin supplements. We had what we then considered a pretty healthy and well-balanced diet, supplemented with a carefully researched and tailored regime of vitamins and minerals. It seemed counter-intuitive for me to stop all supplements immediately, at a time when my body was particularly vulnerable, on the basis that the medical profession had no evidence of the extent to which vitamins might interfere with the effects of the chemotherapy on the tumour. Spot the double negative? 'We don't know if it might not work'. For every study that indicates that a particular product helps fight cancer there's another that says the same product may impede treatment. And when you're that scared rabbit in the headlights of the doctors and nurses and they are saying that vitamin C might encourage cancer cells to grow, and live yoghurt might introduce infection to your immuno-compromised gut, you do what they tell you. More or less. At least to start with.

Weekly chemo is pretty punishing on the body, particularly on the blood and the digestive system. Chemo kills quick-developing cells, which include gut flora and blood cells as well as cancer cells (and hair follicles, obviously). Weekly doses gives the body less time to recover between 'kills'.

I started to feel quite strongly – and conversations with many other people backed this up – that my body was telling me it would cope much better with the side-effects of the treatment if I gave it a bit more support. In the US, the use of complementary medicine alongside chemotherapy (not as an alternative) is increasingly supported. There's growing evidence that many vitamins and supplements not only help to counteract the side-effects, but can potentiate the primary effect ie killing the cancer.

So since the middle of September I've been taking lots of carefully researched and selected vitamins and minerals. That's when I started on weekly chemo. It's also when tests indicate the tumour really started to shrink. My blood counts have remained pretty stable and more or less above the red lines where the medical protocols dictate treatment needs to be withheld for a bit (I did require a transfusion when my red cells went too low, and missed a week when my platelets plummeted, but that's well within what's expected on the weekly regime, and I have managed to avoid the prophylactic antibiotics with which they threaten me on account of low white cells). So far so good.

I'm not suggesting for a moment that this is a definitive list of unequivocally helpful supplements. I do feel quite strongly that it is working for me. For the sake of the record, here are the main components of my chemo- busting supplements:

- [The herbalist] has prescribed a mixture of plant extracts including willowbark, birch and turmeric, known for their cancer-fighting properties, and horse chestnut to strengthen my veins (which take quite a pummelling as they transport heavy toxins around the body, and quite a puncturing with all these needles). I find it rather comforting to be dosing myself with extracts derived from strong, stable, friendly trees. I also take turmeric capsules.
- I boost my immune system with echinacea (which we've taken for years to ward off various lurgies), and a more esoteric mushroom complex (which I think owes its commercial existence to work done on treating HIV). The mushroom complex is also supposed to promote hair-growth – which may be part of the reason why I currently have a bit of grey fuzz covering my scalp. I also take Lycopene, an alpha-carotene derived from tomatoes which is quite a powerful anti-oxidant.
- When my platelet count went a bit low I started taking 2g of vitamin C each day (Dee found some research suggesting this was a good strategy) and since then it's been on the way up.
- Vitamin E helps with the absorption of iron and hence with keeping the red cells above the danger zone.
- Apparently vitamin D deficiency is a known factor in cancer development, and ninety percent of women in Scotland are vitamin D deficient, which accounts for some higher cancer rates than women in the south of England where other factors are the same. So said the lovely oncologist I saw last week. I take large quantities of vitamin D, and get as much sunshine as is possible in Edinburgh in November.

Fresh air and exercise continue to be vital strategies. Our diet hasn't changed much, just a few tweaks around the edges (eg prunes and linseed help the digestive processes along, dried apricots are good for stimulating red cells) and [Veronica's] meticulously planned and prepared, healthy and delicious vitamin-packed repasts. I'm a walking biology lesson, fascinated by my weekly haematology and blood chemistry print-outs. I often wish I could discuss this with my Dad, I think he would have enjoyed that!

## Appendix 6: Storyboard

Storyboard 2	Diagnosis – awful truth	July
<p><i>Diary: 6 July</i> Sleepless night and J very uncomfortable. Feel awful that we messed about. Got to RIE in good time and things then really moved. Charming consultant who by 5pm had her in theatre for a diagnostic laparoscopy &amp; biopsies. Made bed up in flat, very comfy but very anxious. Jane doing very well.</p> <p><i>Diary: 7 July</i> Plan was to go in for 9 but J called to say not until 11.30 so decided to lift kitchen floor tiles – managed half. Eventually doctor came after 1pm and confirmed our worst fears – plan is chemo to shrink tumour then surgery. Bit shell shocked – went to the dump then got J and back to Glasgow to upset [Jane's mother]</p>	<p><i>Diary: 8 July</i> So many tears shed in the last 24hrs but J incredibly brave and stoical. She told Jane's sister's] last night and I phoned [my sister]. Today we just tried to get our heads around the basics and will now get decorators to do flat, and not bother with the drive for now. Walked around the pond this afternoon.</p> <p><i>Diary: 9 July</i> Managed to sleep ok and J more comfortable with thin duvet underneath. Both [youngest sister] &amp; children [redacted] called yesterday. Did chores this morning then drove J up to top reservoir and we had a good walk in lovely sunshine but she was tired after.</p>	<p><i>Diary: 10 July</i> Feeling a bit better today and oedema in legs not quite so bad although still quite severe. Realised that Reiki may be something that helps and started using it while doing the leg draining exercise. Went for a walk around the pond and a nice evening of just us two.</p>
<p><i>Email subject: Feeling better, sent 10 July 5.06pm</i> Hi [my sister] Just a quick update to say Jane is feeling a lot better today and we are both feeling stronger and ready for the challenges ahead. We have cried a lot and laughed a little, and the general consensus of family and friends is that if anyone can do it, Jane can. She has had a very swollen body which in itself is very strange for someone so slight but we have managed to reduce it quite a bit by elevating her legs in various ways - on a pillow in bed, on a footstool and up against my back! I hope I didn't seem ungracious and ungrateful yesterday about the Emergen-C but we have cut back on quite a lot of vitamins etc as she to take special high protein drinks twice a day and there's loads of stuff in them. I'm waiting until Thursday when we'll have a better idea of the full treatment regime - the milkshake flavours are definitely more to [her husband] liking than Jane's! We have been out each day for a wee walk - I drive to a nearby park and we take a turn around the pond although yesterday we went a bit further than we probably should have done but it was warm and sunny. So we have a plan for us to deal with this and whatever they say on Thursday we'll rise to the challenge and try to remember we like an adventure!</p>		<p><i>Diary: 11 July</i> Bit tired today despite a good night's sleep – J not really used to debilitating nature of situation. Managed to do some work on the report and yet more calls ... Wee walk in Deaconsbank but then a good supportive skype with [my brother 7 partner] this evening.</p> <p><i>Diary: 12 July</i> Had thought of going to shops but couldn't be bothered so just went for a wee walk instead.</p> <p><i>Diary: 13 July</i> J has now spoken to all that need to be told.</p>



## Storyboard 2 reformulated as interview prompts

### Interview 2 13/8/2013

Day 22	<b>Feel awful that we messed about</b> What was messing about? Who instigated that?
	<b>things then really moved</b> How was Jane responding here?
Day 23	<b>confirmed our worst fears</b> What had Jane prepared herself for?
	<b>Bit shell shocked</b> Both of you? How did this manifest in Jane?
	<b>She told [her sisters]</b> How did she prepare herself for this?
Day 24	<b>J incredibly brave and stoical</b> How did this manifest? Might she have expected to react differently?
	<b>[Youngest sister] &amp; children then [Younger sister] called</b> How did Jane react to these calls?
Day 26	<b>Leg draining exercises</b>
	<b>Just us two</b>
	<b>Challenges ahead</b> What did you understand these to be?
	<b>We have plan to deal with this</b> What was this? How did Jane participate in this?
Day 27	<b>J not really used to debilitating nature of situation</b> How was Jane responding physically at this time? How did she talk about what was happening to her?
daily	<b>Walks</b> Throughout this section, when Jane was not in hospital, a walk of some sort became part of the routine. Who instigated these? How was this negotiated?

## Appendix 7: Interview Transcript

**Interview Two 13 August 2013 at 11.00 in Interviewer premises, duration 51m**

Interviewer: So this is the second interview and this is looking at the events that took place between the 6<sup>th</sup> and the 10<sup>th</sup> of July and 2011 and you've called this diagnosis and the awful truth. And is there anything you want to say before I start?

VA: No, no, no, it's fine.

Interviewer: So one of the first things that I've noticed from your diary was that you felt awful, that you messed about and that was before you went up to the Royal Infirmary and I suppose there's two things there. One was what was the messing about and the other bit was who instigated that, was that you, was that Jane?

VA: Um, well, to answer the second one first, I don't, it wasn't that the messing about was instigated, it that's more I suppose a reflection of what what happened um going right back to the getting off the train on the 15<sup>th</sup> of June and having that conscious thought that Jane's abdomen was very swollen, there was something seriously wrong, it looked like, it looked like ascites um but instantly dismissing it um because I, obviously neither wanted it nor I think could cope with that being the fact or being true and then because of being displaced, of not having a GP um it wasn't obvious where we would go for help or where she should go and she, Jane certainly wasn't directing anything she wasn't saying oh, I think we should do this or or I think I should do that and I suppose with hindsight she was very much relying on me to either say oh well I think it's this this or that um and this is what we should do and so I was doing a fair amount of that kind of placating and home remedies um but then we'd had the episode of going to the hospital in Glasgow and that having um this strange outcome of UTI and constipation then going, finally having a GP going to see the guy and um him going along with that ... but that had all taken time, it had taken, I don't know at least two weeks and so it was time which again with hindsight wouldn't have made any difference but at the time it felt as though we were messing about and that Jane was just suffering hugely with the discomfort with the pain of this very swollen abdomen and it it it had absolutely got to a I suppose a kind of breaking point that unlike being pregnant where her waters would have burst, um she just looked as so she was going to burst because it she was so swollen um and ... so I suppose I was also blaming myself that I should have been more insistent that we go back to the hospital or we try and see someone else or by the time we'd gone to the GP that we'd ... instead of just accepting him going along with the diagnosis of constipation I should have insisted at that point, hang on a minute do you not think this is this something, more than that look how swollen she is, why didn't I point that out. I didn't point it out because I didn't want to believe that it wasn't anything that it was anything more than constipation ...

Interviewer: And that's obviously very much from your perspective did Jane describe all that as messing about as well or was that just part of her passivity, that she was just going along with how things were unfolding?

VA: No, she she never said anything um and yes she was just in this very ... passive mode that I suppose was starting to look quite anxious and frightened because it was so abnormal um she didn't say but I think she must have known.

Interviewer: Okay ... so the next bit then got to the Royal and things really moved and you mentioned just a kind a list of things that happened but how was Jane in that process, I'm wondering how she was?

VA: Um very much relying on me to to lead to take her to to guide her, to find well to drive through from Glasgow first of all, to get to the right bit of the Royal, to go to the right car park, to then find our way once we got there um ... having said that I think as as I remember when we got to the reception desk where you you say that you've arrived um she went forward to, well we kind of both went forward to but she she said her name um ... and then we were told to wait in an area for ultrasound but what was very strange and I think what was very difficult for her was that the the unit in the hospital um is both for women with gynaecological disorders but also for women who are pregnant so most of the ultrasounds and certainly all of the other women that were waiting um were obviously pregnant um and Jane looked both older and ... whilst at first glance she might have looked pregnant she also didn't look right so she she was swollen in a different way um ... and then things really moved because I don't know how long we waited but only 10 or 15 minutes I think and then her name was called and I asked that I could go with her and that was fine and I think she had to put a gown on which I helped her do and then we were taken through to the ultrasound room and um I helped her up on to the couch, examination thing whatever it is and the radiographer was on one side and I sat on the other um and they started doing the ultrasound ... and quite quickly she could the the radiographer could see on the screen that there was a mass and she started measuring it and called to her colleague to agree the measurement and they were talking about 12cms and things and then it it was I was making reassuring noises but we were just kind of exchanging looks that said yes there is something and um their looking to see what it is um and she ... the radiographer finished what she was doing and cleaned the jelly off Jane's tummy and then we went back through to the area to wait until somebody else came ... and again it wasn't very long before a nurse, a kind of more senior nurse came and we were taken through to um an examination room that had an actual bed in it and I could really sense and see that things had had changed that they, there was that sort of tacit, shared knowledge that this was something seriously wrong that Jane was in considerable discomfort um I think she was even offered um analgesics um and we helped her up onto the bed and made sure she was more comfortable and they explained that that they were waiting for the consultant to come down and see her but that it would take time because he was in theatre so it was just a question of waiting but .. we both felt, Jane certainly felt that that was okay because finally something was going to start happening, something

was happening, somebody was coming, somebody was going to sort this um and so we waited ... .. and eventually the um female doctor came ... um in theatre scrubs and she kind of bounced in and had a bit look but not anything very much and she would have said who she was but she was barely there but then she said that in fact um [surgeon] would come and see but he was still in theatre so we waited again and I think they maybe offered us teas and coffees and lunch and stuff like that but neither of us were hungry um I can't remember whether we had any food or not and eventually he came and um was very smiley and charming and um ... asked Jane all sorts of questions about her medical history and how long this had been going on for and things and then he wanted to do an internal examination and so she had to get off the bed that she was on and go to a couch with stirrups which we managed to do um but she was in an extremely uncomfortable position then and he tried to examine her and it was excruciatingly painful and he didn't really try very hard um but just sort of said no no, it was okay he would um he would leave it um and that what he really needed to do was to take her to theatre and do a diagnostic laparoscopy to see what was going on and that he could get her into the end of the list that day um and so that was the plan um but she needed to go and have a chest x-ray and things like that so then it was just more waiting um waiting for porters to come to take her to have an x-ray and then waiting to be taken up to the ward and things and I think a porter came and took us a long long long corridor and eventually we got to x-ray and she had a chest x-ray done and then we were sitting waiting and suddenly the surgeon reappeared and said right, that was it she, he was ready for her and he whisked her off upstairs um well we both went up to the ward and the ward staff gave us a gown and things and got ready for theatre and off she went and that was it then, there wasn't anything else I could do, there was no point in me waiting I just had to leave the um

Interviewer: How was she when she heard she was going to have to go to theatre that day?

VA: Oh, she was excited, she'd ... she seemed quite quite small a lot of the time and if I say she was almost child-like I don't mean that in a derogatory sense but there was this kind of wide-eyed innocence and part of that wide-eyed innocence was curiosity to what was going on, what was happening she she hadn't ever spent a night in hospital all her adult life um even though she'd had minor kind of traumas and things she'd never actually had to stay in hospital and in the previous year she had actually injured her finger and had to go to theatre to have that fixed but it was all done under local anaesthetic and she hadn't had to stay in and I'd looked after her and that had all been fine so she was she was just interested, she was um I think it was almost part of her coping mechanism was to ignore the fact that it was her body that was being looked at and poked and prodded and examined um this was um this was something exciting that was happening. Her father had been a laboratory technician and so she had that kind of sort of medical curiosity of what's going on wanting to know and and I suppose consoling herself with what her dad would have thought of it and um how she would tell him all about it ... ..

Interviewer: I'm just looking at the time and I think we're going to have to sort of move on a bit. The next comment was the next day after the biopsy and things, your worst fears were confirmed and I'm just wondering what had Jane prepared herself for?

VA: ... um ... .. curiously Jane had always thought and we'd kind of, it had been mentioned in previous years, in the past that she she would get bowel cancer, she always thought she would get bowel cancer and the other thing that was odd was that she used to get a sort of tweak um I think it was on her right sometimes when she turned in bed and things and she she used to say jokingly oh that's my twisted ovary um and of course neither one of us thought or said anything beyond it was just one of those kind of jokes as it turned out it was on, the the mass was on the left side ... but then there was a there was a gap between her coming back from theatre and being on the ward and my coming back to the hospital so I don't know at what point she must have realised, whether she realised ... actually I think, yeah, she knew when they did the ultrasound because we both knew that there was a large tumour and so then what she was preparing herself for was how they were going to sort it, how they were going to get rid of this thing and make her better and so she was she was quite upbeat almost um that finally there was something to name um although at that point they wouldn't say anything beyond, yes they had found something um and they they'd taken the biopsies but until they got the results of the biopsies which would take a week they wouldn't be able to to say any more and that the next step was to be seen by the oncologist and he could only say what treatment what the precise treatment would be once they knew what kind of tumour it was but yes there was a tumour and yes she would need chemotherapy and then if they were able to shrink the tumour they would the surgeon would then be able to remove it so although the news was devastating it seemed that there was um a positive plan of something to do ... the the there was going, the hospital ... um there was action to take ... ..

Interviewer: I'm sort of getting this sense of Jane not delivering herself up, but she's very much there to be to be sorted.

VA: Yes, yes – they're gonna fix me

Interviewer: So that was in a sense what she was preparing for, okay.

VA: But then I think the first notion of what that might entail um but at yeah

Interviewer: And when she heard some of what it entailed, the chemo, the erm possibly surgery

VA: I don't know that she had any real kind of experience of what chemo might involve, I mean she knew what chemotherapy was and she knew that it could make you feel quite ill and things but she was she was a very trusting person so she trusted two things, she trusted that the health service would would do its best and and she trusted me to look after her, to to take care of her and to to make sure that they did their best ... ..

Interviewer: You mentioned being shell-shocked and I'm assuming that's probably you but what I'm wondering not really clear from what you've said was it Jane, would you describe Jane as being shell-shocked as well or less so than you were?

VA: I, I think less so than I was, I think I ... when they eventually said that, that she could go and that we were to go back the following week and we'd get an appointment to to see the oncologist um and we were given the discharge letter to give to our GP but they don't seal them any more so it's quite easy to to open it and and see what's in it. In fact we might have even been given two copies, I can't remember now but I certainly have a copy of it um and I read and more or less understood what the letter was said that that this was a an advanced tumour that had already spread um quite extensively within her abdomen and that this was very bad news and my nursing experience um was not good ... even my personal experience of women with ovarian cancer wasn't good, people, this was not something that people got better from. However, um Jane was fit, was otherwise fit and healthy so I think although I was devastated, I was absolutely shell-shocked by the horror of it um she, very much believed that she was strong, she was fit, she was healthy and that that everything was in her favour and that if anybody was going to um respond to um treatment, she would that she, she could get better from this ... ....

Interviewer: So that night, I think she phoned and erm told her sisters. How did she prepare herself to do that?

VA: ... Erm, well, we'd we'd driven back um and told her mother and I, I think in telling her mother um as a linguist Jane was very good at rehearsing what she wanted to say and so it didn't really matter whether she was gonna say it in French or German or in English she would rehearse and she would have rehearsed in her head what she was going to say and what the um the the way in which the news would be presented um so yes, there was bad news but there was a positive message and the positive message was that the surgeon had taken the biopsies to identify what kind of tumour it was and the oncologist would then know what kind of chemotherapy to use and the tumour would shrink and the surgeon would then remove it and so that was, it was very much presented as a complete package um ... without any kind of question that maybe the tumour wouldn't respond or the surgeon might not be able to remove it or that even surgery might not be such a good idea because of the other things that it might entail. None of that, um she wasn't aware of any of that and so none of those kind of things were raised.

Interviewer: And a similar process then of telling her mother ...

VA: So in telling her mother yeah she um [talking over each other] would have gone through the the, we would have had conversations in the car about what it was on the way back and so on and she would have already started her own internal process of the story that she would tell and then so she the first run of that, the pilot if you like, was telling her mother in such a way that yes, of course it was going to upset her mother, it was awful news for her um but she had this upbeat message um and

similarly with her sisters who are quite different in their um ... both in their own experience um but also in the in the way in which they respond to such news ... ..

Interviewer: Another description you have of Jane in your diary was that she was incredibly brave and stoical.

VA: Mmm, I think, yeah that's it that she ... it was very much this attitude if anybody was going to beat it she would and that we were a team, that she wasn't um I mean I was very quick to reassure her that she wasn't gonna face any of this alone, that I would be with her all the way um that she wasn't to worry about anything at all, you know on any level um if there was anything that she was concerned about, that she was frightened or anything she was to say um and um that that there were supports around her for for all that she needed so um ... I don't know now whether she had for some time had this internal wondering puzzle of not feeling quite right wondering what was going on, finally there was an answer, there was an explanation whether there was almost some kind of relief. There wasn't anything obvious to suggest that, I think it was, much more that she just ... yes there was something wrong but there was a plan to deal with it and um ... yes she was just brave.

Interviewer: Mmm, and is that how you and she would have actually expected her to be. You might not have used those words but that that's, would you have expected her to react any differently in a sense with difficult things?

VA: No, I don't think so um my only previous experience was when we were .. um two or three years previously we had been away on business in Birmingham and had received a phone call or a text message from her sister to phone which we did and it was to say that her father had collapsed and died very suddenly um whilst out walking in a park and her reaction then was one of um obviously huge horror and upset that her father had died suddenly but she she very quickly recovered and promptly started writing about it um so ... I didn't, I didn't think about how she might react and I wasn't surprised but equally I wasn't surprised by the way in which she did react ... almost took it in her stride

Interviewer: I'm just really struck ... by that about taking something as huge as that in your stride. What was your sense of how she was responding?

VA: ... We were very strong together though um there was a huge strength between us and um I think for many people they do feel to some extent utterly alone and and frightened and ... what I didn't want her because I knew the my, my imagination was running away with with all the things that she was gonna have to face and, and and so on um but I, I didn't want her to be fearful, I wanted her to feel safe and as protected as possible, that she wasn't alone and we'd make it as easy as we could ... that she, she wasn't to fear that she would be in pain or that it would be ... to horrid or whatever, that it would be okay and and that, that was right from the, yeah the diagnosis that, that was hugely important that, that um ... that I was there um or that there was someone there that was with her all the way.

Interviewer: I sort of get the sense when you say that would just say that she was quite passive to start with there was something about her being carried is an impression I get in, in what your saying there just now is that she could handle all that because she was, she was safe and she was

VA: Yes, yes

Interviewer: I'd say carried, I feel there was one of these litter chairs or something like that

VA: Yes, being borne on a sedan chair indeed yes, yes, yes ...

Interviewer: The next day [Youngest sister] and the children and then [Younger sister] called so how was that for her?

VA: Um, well [Youngest sister's] the younger of her sisters well relatively small children um and they were very sweet and they all trooped in um Jane was, was sitting in an arm chair with her legs elevated because her legs were very swollen and oedematous um and she really did look quite pale and poorly um because she been, I mean she'd been through the physical disruption of a general anaesthetic and then all of the psychological trauma of, of what had happened and she was putting on a brave face but the brave face would slip um and she was very touched with the children and their little drawings and get well cards and um the warmth I think um and [Youngest sister's] married to a pharmacist so although she doesn't like anything to medical and specific she's also quite stoical and sensible as well um [REDACTED] on the other hand is, is a little bit more histrionic and um I think when she, she came later on in the afternoon and she said something like oh my god um you look awful and couldn't, couldn't bear to stay and Jane was very upset by that um that, that was really hard and I was annoyed because I, I thought how dare you, do you, you know however awful it is for you, it's ten times worse for Jane so you know you've got to put on a brave face for her um and of course if the other sisters either of them was upset then that was even more upsetting for Jane's mum um but it was, was like a series of challenges you know as the, the story unfolds, the telling of the bad news is, is broadcast um first from the, the immediate members of the family um and then beyond. It gets easier, each time you tell it you own a little bit more of it yourself and I think that was part of what happened for her that, that although it was difficult to tell the story she then the reward was the strength that she drew from other people by their expressions of love and support for, and good wishes for her returning good health ...

Interviewer: There's a couple of things that I haven't actually got questions for but erm you mentioned doing the, the leg draining exercises.

VA: Um, well as part of the massive swelling in the abdomen so as the fluid continued to accumulate it had spread to her legs and her legs were very, very swollen um so I devised, I can't remember if I, I probably, possibly looked something up on the Internet but I devised this method of lying her on the floor and elevating her legs up against my back and just basically sitting there um to, to really kind of



try and help the fluid drain out of her legs um and she had also, her albumin levels were very low um which is feature of the ascites and so she was on these um protein-rich drinks to try and bring her protein levels back up and that was all supposed to be helping so but it was also an opportunity to do some sort of relaxation um hands on healing stuff to, to try and help her feel a bit calmer, feel like we were doing something um ...

Interviewer: Did she actively participate in these things or did you have to persuade her that this was a good idea?

VA: No she didn't need any persuasion, I mean I think she was just, she was just glad for anything that was gonna help to make her feel more comfortable. It wasn't, wasn't hugely inconvenient to her, all she had to do was lie on the floor and I had a, I don't know a duvet cover or something I put on the floor for her so it was easier to lie on and things ... the one thing we did try and do was not do it when her mother was in, we used to wait until her mother went out for her paper or something and then do it um

Interviewer: Why was that?

VA: Um ... I think because Jane was always concerned not to upset her mother or I suppose to particularly draw attention to the needs of her, her difficulties ...

Interviewer: So she was protecting her mother?

VA: Yeah, yeah

Interviewer: And you were obviously living with her at that period as well?

VA: Yes, we we were still staying there, we had the flat but we ... we were working ourselves up into how we were going to be in the flat whilst it was renovated.

Interviewer: So, at this early stage some of Jane's attention would be focused on her mother and making it all right for her mother?

VA: Yes um her mother when she's upset wrings her hands and um you can see that she's upset and she, she tends to go very red and Jane was obviously very alert to this and I think that made it much more difficult for Jane and it was a small flat um it wasn't comfortable we were there with our cats as well and although we were all getting on and everything was fine it, it wasn't easy and I suppose neither of us were really relaxed or felt particularly relaxed there um on top of everything else that was going on, it wasn't easy to just kind of chill and be ourselves.

Interviewer: So that kind of really emphasises the other bit that I was going to say which was that just us two bit that actually these times just to be on your own

VA: Yeah, yeah, I think just to ... to give what had happened its place and to give us the, the sort of time and the space to just to come to terms with it, the enormity of it um ... with, we weren't consciously on our best behaviour staying with her mum but obviously you do do things differently when you're staying with somebody else,

in somebody else's house um and ... we, we didn't feel we could truly relax unless it was just the two of us ...

Interviewer: You mention in an email to, to [My sister] about the feeling stronger and ready for the challenges ahead. What do you think Jane understood these to be?

VA: oh, just in a very simple sense the chemo, whatever that might involve um and we knew that meant we had to go to the hospital every few weeks and, and have various drips and things and it took a bit of time and so it was time consuming and then waiting to see how the chemo worked out and then um getting ready for the surgery and I, I think at that point she thought that well we hadn't seen the oncologist though but we thought that it would be a few months of chemo and then possibly by, into the autumn that, that she would have the operation um and it was very much that, that kind of timeframe ...

Interviewer: The other thing that you mention that in ... is we have a plan to deal with this, so what was your plan to deal with it?

VA: That ... we, the NHS would, would um do what it had said it would do which was the chemo and then the surgery and alongside that we would do whatever else we could do to maximise um the benefit or the, the yeah, the benefit of the treatment and Jane's well-being particularly for her to be strong enough I think to deal with the surgery, that she would be well enough to, to cope with that, because she didn't, I mean at this point she really didn't feel very well, she didn't, she didn't feel very strong um because she was so disabled by the, the degree of the swelling and discomfort.

Interviewer: Sorry, I've got this question about how did Jane participate in this but it sounds as if that it was a bit more of the ... not passivity but that sort of taking the lead from you?

VA: Yes, yeah um ... she, we were still working I mean she was still doing interviews um and um ... she would be propped up on in her, in her chair with the lap table and her lap top and um the phone and her mother would go off and do what she did and I would get on with all the other things that needed to be done and Jane would carry on doing interviews and transcribing them and drafting reports and, and so on and, but I think that although in some ways that might sound awful in other way it was quite good because it, it was something to distract her, it wasn't particularly difficult work um and she liked talking to people, she liked finding things out so it was, it was ...

Interviewer: I suppose what I hear is just how in the midst of all that was really awful not being well that she actually I suppose some part of her was carrying on as normal.

VA: Indeed, there was as much um carrying on as normal as possible um and I think ... this massive thing had come in from left field, completely knocked us off our perches um and we'd both

together and independently sort of dusted ourselves down and got back up on the perches again and said uh, right, um okay. But there was also ... very definitely for Jane this sense that there was a, there was a real plan and that, that was what was going to happen and, and it was quite matter of fact, a bad thing has happened, but they're going to fix it.

Interviewer: So that she was relying on you for the plan on her part of the plan was just to carry on and do her bit?

VA: Yes, yes, to, to um ... to make the best of, of, of what could be done, yeah ... ..

Interviewer: On the 11<sup>th</sup> of your diary you say, and I suppose I found quite a, that Jane's not really used to the debilitating nature of the situation.

VA: No, she was very frustrated by, er she was until the previous month she had been you know up hills and we'd gone on a long, long cycle you know round island day trip, no sorry, trip of a number of days um we were both quite active people and suddenly she ... she was just puggled by even a small walk um and she was gauging how well she felt by the extent around of the pond she could get in the local park and um so she was then using that as a, I suppose also to drive herself to, to push herself, right well, I can manage halfway round one day, can I manage all the way round the next and then twice round the third day um and was, was not patient to, for this to take time she wanted to be better ...

Interviewer: So how did she talk about what was happening to her?

VA: ... She didn't really um ... there was the official line, this has happened, this is what it is, this is what they're going to do ... um and move on to the next thing um I don't, don't, didn't have then and I don't even now um don't recall that she appeared to need or want to talk about it. She was quite a, a factual person, um she was quite, quite deep I suppose but she did just accept what was said. If that was what it was then that was it and there was no point in going on about it um.

Interviewer: Did she ask you, what you thought?

VA: ... I know we went through the, the discharge letter from the hospital a few times and she read it quite a few times and there's, there's quite a lot of technical terminology in it um some of which I had to look up because I couldn't quite remember off the top of my head what things meant um but I remember explaining it to her and um saying that it was if the tumour had bloomed that, that it had grown to a particular size and then um it had fired off lots of little seed cells and these were had, had kind of attached themselves um inside her, her abdomen and the lining of the abdomen and on the underside of her diaphragm and the underside of her liver and, and so on so the chemotherapy had to zap all of these little um seeds as well as, as the main tumour but she was, that was what she wanted was the kind of pseudo-scientific explanation of, of what was going to happen um and then that the tumour would shrink and it would shrink to a size that, that Graham the surgeon could remove it .. and that, that was all she wanted.

Interviewer: So that really, your sense was that was all she needed in terms of an explanation?

VA: Yes, yeah, yeah.

Interviewer: The last bit that, that I've got really and you've answered a bit of it in that last question was about the every day there's something about the walks, there's a walk, there's a good walk and then quite often is a wee walk ... so I mean you've said a bit about that but I think I was um that, that was how she was gauging, how she was doing and how much of a walk.

VA: Yeah, yeah, that, that was her measure if um when we first got back to Glasgow after she'd, she'd had the, the diagnostic lap um and she obviously had some discomfort because she had little, couple of little wounds from, from the procedure and there was a fair amount of bruising so her abdomen aside from the swelling um that had gone down a lot because they'd drained off a lot of fluid but she still had these quite swollen legs and the whole thing was just had taken a lot of out of her, knocked the stuffing out of her so it took a few days to recover so that was just small walks um maybe just round the block um then I took to, to taking her in the car to the nearby park and walking round the pond or one side of the pond and so on but she drew such strength from being out in the fresh air, from seeing birds, she everything was she wanted to see nature, to see birds to see plants, to see trees um and wasn't interested in going to shops or anything like that, she wants to be out in the countryside and the nearest that she good manage was this nearby park um.

Interviewer: Cos, one of the things so that she herself would have instigated the, the, the desire to go for a walk for instance, that that was something that she would have said lets go for a walk?

VA: I think, I mean it's almost impossible to say, it would be a mutual thing we would both, we would both expect to go out every day for a walk, we always had um it was either a walk or a cycle and it was a walk of at least an hour's duration um so it was of reasonable length and at reasonable pace and suddenly we were reduced, we were reduced to sort of twenty minute waddles um which was the really strange thing um

Interviewer: So a twenty minute waddle

VA: Yeah

Interviewer: And over time she was able to get further over the twenty minutes?

VA: Yes, yes, we didn't, I mean surprisingly I don't think it took that many days for her to, not get back up to speed again but for her to feel, okay, yeah I can, I can get a bit further now, I feel more on top of things um

Interviewer: But an hour's walk would have been beyond her at that stage?

VA: Yeah, I think so ... yeah, I knew not to push it, I knew and I mean there was one day um we'd gone up, there were, there were reservoirs a bit further out um which was more out in the countryside and we'd gone round one of the reservoirs

and she was very tired after that um and I, I remember I said to her well you know, you push yourself round that's fine but, but you're gonna have to take it easy when you get back and I was touching on um ... a kind of joke of being in training for surgery so yes, it's important that you learn to walk when it feels a bit uncomfortable and a bit difficult because after you've had the operation then um you, you will feel sore and you won't feel like doing too much but so yes, she was, she was preparing herself as well as pushing herself ...

Interviewer: So as you say the walks were training for possibly for the surgery

VA: Yeah, yeah

Interviewer: well that's, I haven't made any other notes for myself about that and so I'm wondering if there's any thing that you feel that you haven't had an opportunity to say or that's important because I'm also at that point you were living in Glasgow but you were doing a lot of work in Edinburgh so you were having to leave her at times?

VA: No um the most I would leave her would be to, to nip down to the nearby supermarket and that was 10 minutes away um any time that I went through to Edinburgh Jane came as well and I had stayed the first night when she was in the hospital, I stayed myself in the flat and um we'd already made provision that we could stay in the flat even though things were being done um and that was also part of the I suppose kind of distraction um of, of her illness and her situation was that we were, we were very much planning what we would have in the flat and how things would be and I was arranging for various tradespeople to come but we'd also made the decision um once we knew how seriously ill she was that we weren't going, I wasn't going to try and decorate the flat myself um with her help, we, we would get men in to do it um and so there was there were those kind of arrangements going on as well ... but the energy for that was very much um because we wanted to be in our own place and so that, it was a nuisance but it, it was a good nuisance ...

## Appendix 8: Hospital Letter

NAME: -----

This lady's case was discussed at the Combined Gynae Oncology Meeting and I saw at the clinic thereafter. As you know she has now received 3 cycles of three weekly Carboplatin and Paclitaxel chemotherapy for a grade 3 stage 3C serous papillary ovarian carcinoma. Previous laparoscopy had shown the disease to be extremely extensive and certainly inoperable at that point. Unfortunately the lady's CA-125 level has gradually crept up on chemotherapy having been 8967 at the start rising to 9184 after 2 cycles. In terms of a percent change this is clearly minimal. Radiology from pre-chemotherapy compared to post chemotherapy suggested the disease has remained largely stable but that there is worsening hydronephrosis (in the face of ongoing severe left hydronephrosis). There had been some resolution of the lady's pleural fluid.

Discussion at the Multidisciplinary Team revolved around the fact that this lady appeared to have very resistant disease and that we should change her to weekly Carboplatin and Paclitaxel. In addition it was agreed that we should consider stenting the right kidney.

When I actually saw the lady at the clinic she told me that symptomatically she felt much better since starting the chemotherapy with more energy and resolution of her abdominal pain. She admits some abdominal distension still persists. In terms of toxicity to chemotherapy the only major side effect has been alopecia. Fatigue was an issue after cycle 1 but this has decreased as time went on.

In terms of urinary function the lady describes some post micturition dribbling although this predates her chemotherapy it has not improved. She also feels she may have incomplete emptying of her bladder. She has no difficulty starting the stream.

Clearly we need to work out what level the obstruction of the urinary tract is. It is clear that her complex left pelvic mass that is enveloping the distal left ureter and almost certainly responsible for the left-sided hydronephrosis. It is difficult to know whether it is this mass that is also causing the right-sided hydronephrosis or whether it is a problem with bladder emptying that is causing the right-sided hydronephrosis.

Therefore I spoke to the Urology Fellow today. She felt that we should perform a post micturition ultrasound and if there was not much residual urine then we should arrange for stenting certainly of the right kidney. I have therefore requested a post micturition ultrasound done and when the result of this is available I will speak to Urology again.

In addition we discussed weekly Carboplatin and Paclitaxel and the lady consented to change from the three weekly regime to the weekly regime.

## Appendix 9:A Return Enhanced

Diagram to illustrate the relationship between Schiller, Heidegger, and Galvin and Todres based on an earlier diagrammatic interpretation of Schiller (Higgins, 2008). It is a return enhanced to the initial understanding of Schiller's drives enhanced by the Heidegger's (1993) later work and most recently Galvin and Todres (2007).

